In Our Own Words

First Hand Accounts by Adults on the Autism Spectrum

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These stories have been provided to inform readers about issues and information related to the autism spectrum. Their inclusion in this publication is not an endorsement of any treatment, program, product or service. While these stories are the personal accounts of the individual authors, every attempt was made to respect the identity of specific individuals through the use of minor edits.

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FOREWORD

by Lee Steel

As a parent of a child with autism, I have had so many questions that professionals or books could not answer. I heard many theories and explanations, but I wanted to understand the experience of being autistic from the perspective of those who live with this condition. For these individuals, the thread of autism is woven into all their life experiences, from childhood through to adulthood.

I know I am not alone in my search for inside knowledge. Perhaps that is why books written by adults on the autism spectrum (Temple Grandin, Donna Williams) have proven to be so fascinating and helpful to so many of us: parents, educators, friends, and physicians. Why guess when we can ask?

I have had the privilege of meeting and speaking with adults on the autism spectrum through The Autism Group. I have learned so much from these individuals, and I was most excited when Autism Society Ontario was able to arrange funding in order to publish their accounts in their own words.

It is our hope that this compilation of experiences might reach a broader audience. The recurring stories of indomitable human spirit found in this volume are an inspiration to those of us who support our children, our friends, and our fellow workers on the autism spectrum. Some readers may strongly identify with these stories and—perhaps for the first time—realize that others have felt and experienced some of the same things that they have.

Learning from these first-hand experiences has forever changed the way I parent my son. This new knowledge has opened a window for me. I now have a better grasp of both the difficulties that my son faces and the gifts that autism has brought into his life and mine.

We live in a world that is not always accepting of differences. At the core of each of us, there really are no differences. We all desire true acceptance, love, and understanding. It is our hope that you, too, will be inspired by these writings.

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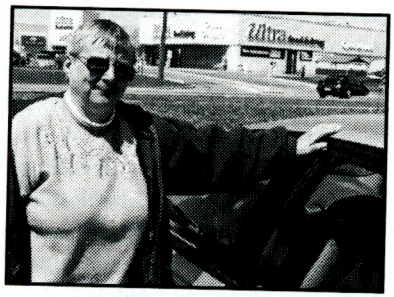
INTERVIEW WITH PAM NEWMAN BUTTON

The following is excerpts from a conversation that took place between Pam Button and Margaret Spoelstra, Executive Director of Autism Society Ontario. This dialogue was originally recorded with a camcorder during a walk with Pam's two dogs, Susie and Teddy to a park, near Pam's apartment. Vern Nicholson transcribed the audio contents of the video for the readers of this booklet.



Margaret: What do you like about living there?

Pam: I like it because it's very handy for the dogs going out the back door... and I'm not...I have nobody under me, or each side of me, which is good.

Margaret: When did you first know that something was different?

Pam: Well, I know I spent two years in kindergarten. I didn't talk 'til I was six. My very first teacher was very strict and hit and shook anybody that was mentally challenged. She did a lot of shaking and hitting me, and I didn't know why. That was my first year at kindergarten. My second year at kindergarten, she got a little better toward the middle of the second year, because one neighbourhood boy squealed on her and told my mom. So my mom went to the principal. I guess the principal talked to her and she was alright the rest of the year. Then the following year, I was in grade one. I had a superb teacher.

Margaret: What made her so superb, Pam?

Pam: Because she helped me. She helped me use the telephone; she worked with me...very patient, you know. And I thought school wasn't so bad after that.

Margaret: What was hardest for you? What was it like being with the other kids?

Pam: When I first went to school, I thought kids were just objects. They were harmless because they didn't shake and hit like the teacher did. They were just like objects rather than...you know. And I didn't want to play with other kids much, but when I did play with them, I preferred to play with boys because I liked the boys' toys.

Margaret: And what was it about girls that made it difficult to play?

Pam: Because they liked skipping. They liked dolls ...I didn't like dolls. They were more pretty things, you know.
And of course, when I went to school...I'll give you an example of grade 1. Of course, I was starting to get verbal at seven, and the teacher, the grade 1 teacher, told me, "put the books underneath the desk." I didn't know what she meant, so one of the kids across from me said, "under here!" Then I knew.

Pam: I was in Hamilton till I turned eight; then our family moved to Ancaster. Of course, when I was a kid—and I still do it now—whenever I pet an animal, I have to take off my gloves. I have to feel the fur, and I still do it right now. I was in Ancaster, and I liked it because it was country and fields and wildlife.
Even though I didn't want to play with other kids at that time, they wanted to play with me. Some of them were mean and thought I talked baby talk.

Margaret: What kinds of things did they do? When you say that they were mean, were they teasing you or what happened?

Pam: Well, ...the ones that were mean, they'd say, "You talk funny! You talk baby talk." As I started to talk a little better they said, "you're talking better," you know. Of course, I wasn't aware of it. Some of the kids asked me if was I in a car accident and was I deaf. I didn't know..."What do they mean by that," I thought. That was all I had at that time, which is mild compared to what I had in my teenage years, moving to Oakville.

Margaret: What was that like, Pam?

Pam: When I moved to Oakville, I was in a regular grade till I was in grade 7. Then my parents put me in a boarding school in Montreal for emotionally disturbed kids. I was 13 at the time.
During my twelfth year, I started doing little temper tantrums. My psychiatrist who treated me as a kid thought I should go to Montreal. They knew there was trouble arising. When I first went into Montreal, I went from a placid, well-behaved kid to a very destructive kid by the time. I knew I was different and knew I wasn't normal, but I didn't know what the problem was. My family was still in Ancaster at the time. Then, as I came out of Montreal, we had to move again because dad worked in Oakville. He couldn't commute back and forth from Oakville to Ancaster. He got too tired. So we moved again. My brother moved out of the house. I had to leave my friends in Ancaster. I had to leave my friends in Montreal. It was just too much to bear, so I really had trouble in Oakville: temper tantrums, head-banging.
I was in a regular school in grade 8 for two weeks. My parents took me out because they thought the school was too hard, so they put me in an opportunity class. That's where the

trouble began, because the opportunity class didn't understand me. They thought I was weird. There were mixed slower kids - vocational. The normal kids in Oakville thought I was retarded. After that, I was in a psychiatric hospital twice. The patients didn't understand me either. They thought I was slow and tired. When everybody hated you, you hated your own shadow.

Pam: In the second time in the hospital, I spent an entire year there. Received 18 shock treatments and so many drugs. What rescued me from a life in the hospital was, they opened up a workshop in Oakville, and the director of the workshop took me in and accepted me. That's what saved my life, because there were no other options then. There was no school. But before I went to the hospital the second time, I was in high school for two weeks. They didn't have the right courses for me. I was terrible at doing hair. They had hairdressing courses, and when you're not good at that, you wouldn't last two weeks there. Now, they have vocational courses for kids like me, but back then, they didn't have anything. Luckily the workshop was there, or I would have spent life in an institution. It's just like a dog being rescued from an animal shelter.
It took four years at the workshop before they found anything that I was quite good at, that I'd excel at. They found out that I was very good at silk screening, so they put me in charge of the operation. And I was charged with three other people. We made Christmas cards. Of course, to work with those autistic kids, put them in charge of something. That would kind of get rid of their autism. If they're good at something, put them in charge of something.

Margaret: So being in charge of something was a really helpful thing for you.

Pam: Yeah. So I thought I'd prep up on other factory work and stuff like that. It took a while, and then finally, after the last two years, I thought, "I want my own job." I had worked temporary places before. One place was successful, but the company was moving to Weston. Of course, the company wanted me to go with them. I didn't drive and it was too far for mom to take me to commute there.
So the second job on temporary wasn't successful at all. Then after six years, however—back in 1971—I started my first permanent job. It was washing dishes and labware and setting up equipment in a pollution lab. I was at that job for 10½ years.

Margaret: How did you get that job, Pam?

Pam: I went on my own.

Margaret: Did you?

Pam: I did. Look, most people with autism cannot do well with job interviews. I guess what they liked about me was my appearance, trying so hard at the workshop. I tried for three other jobs at the same time in that interview. So (another company) hired me, and believe it or not, three other companies wanted to hire me too! So I thought I'd try the job (at the first place). It was the best solution. Anyway, I was there for 10½ years. During that time, my medication was reduced a bit. I was on Cogentin. I had severe weight gain, as anti-psychotic drugs do. So anyway, I was on Cogentin; that took the drug effects out of the…

Margaret: Side effects?

Pam: Yeah, the drug effects. So I was able to function better, and I thought, "Well, I would like to drive a motor vehicle." So the first motor vehicle I tried was a moped. It was a motor-assisted bicycle. But a dump truck backed over me. It wasn't my fault. He didn't see me. I was on my way to work at the time. Luckily, I only escaped with a laceration on my left leg.

But I got $3000 - 4000 out of that. The second vehicle I bought was a motorcycle. People thought I was crazy after what happened to me, but I figured, "Well, if you fall off a horse, get back on it." So I got my licence. Of course, it took me a couple of times. I had driven that for three years, I figured if I could drive a motorcycle, I could drive a car. So it took me a while to learn to drive a car, but I finally did. I got my license in '77. I had to try a couple of times then, too. I bought my first car in '78. It opened a door for me.

I started dating a bit. That's when I met my husband. So we started going together. My husband was mentally challenged, but I thought he wasn't so bad. We dated for about a year, and then we became engaged. Got married in '79, but the marriage only lasted five years. But apparently, if I didn't try marriage, I probably wouldn't have…I would still either be living with my parents or living in some residential program. It proved I could live on my own and do those things.

Margaret: Excellent.

Pam: During my married life, I got laid off at my job: not due to inability, but because of the economy during the '80s. It took me a while to find another job, but after three months, I got into a private cleaning company, cleaning schools. I cleaned (a local college). The job hours were from 7:00 at night to 3:00 in the morning, but I figured it was a job. But during that time, there were big men applying for a job, and I thought, "Gee, I'm not going to get this," but I did. They phoned me up and said, "Will you come in tonight?" I said, "Sure." So I was there for 2½ years.

So after that, I got tired of the night shift hours, and the marriage was getting on the rocks. It was getting more exasperating. He lost his job due to inability. My husband worked for about 12 years.
I guess he couldn't stand working and married life too, so he lost his job through poor grooming and lazy work habits. I continued working, and then during that time, he hadn't been able to hold jobs. But I held my job for 2½ years to keep the rent going, even though I didn't like it. I was finally offered a job at the senior citizens' home as a waitress.

Margaret: You've had so many different jobs, Pam!

Pam: But anyway, that didn't work out because I was slow waiting on tables and kept dropping things. Then I was out of work for quite some time. Then we were both out of work. That's when I decided to split with my husband, so I wouldn't feel so awful.

Margaret: So tell me a little bit about some of difficulties that you've had at work over the years? Were there things that were harder for you, Pam?

Pam: Yeah, problem-solving.

Margaret: Like what?

Pam: If something's out of whack, I might panic.

Margaret: Okay. And when you panicked, what was the thing that helped you to stay calm and get back to doing…

Pam: Well, sometimes the other workers would calm me. "Take it easy; it's all right." I'd say, "Come quick," you know.
Now, in my job at a technical company, I had experience with quite a mean secretary. She would say, "There's a cobweb out there. Come and get it." They were only kidding and I believed them. They laughed. They said, "It's just a joke. Can't you take a joke?" That's when I felt like walking out.

Margaret: When did you find out that you had autism, Pam?

Pam: When I was 20.

Margaret: And what happened when you were 20?

Pam: I asked my mom, "What is wrong with me?" I asked that for many years. They kept putting me off. Why did I get behind in school? What went on in Montreal? Why didn't I talk at six? What is wrong with me? So she explained to me that I was a shell baby - shell baby, in a shell - and there was no hope for me, and that I wouldn't be able to read and write. I was reading then. I could write okay, and I figured, "Well, I'm going to beat this thing," you know. I'm going to beat this darn thing. I think I can do better. Basically, I'm going to keep beating it.

So anyway, getting back to my job that I lost at the senior citizens' home, that's when my husband and I split. That was our excuse to split, and I explained to him that he's moving back with his parents and I'm moving back with mine, and there's no money and there's no jobs. I didn't have the heart to say our marriage didn't work out. So anyway, the job...the day I was to leave my husband, I applied for a job with the Board of Education.

Then I had an interview just a day before I left my husband. I left my husband on the weekend. On Monday morning, when I moved back home, I got a call, "Could you start on Tuesday?" Tomorrow. I was pleased. I was a part-time cleaner for two years, then got in as a full-time caretaker. Of course, in that time, they didn't have job assessments for promotions.

Then I was finally divorced in '86, when my permanent full-time caretaker job was successful. Then, in '87, I moved - I stayed at home for a year to save some money - then I moved out again. Been on my own ever since. During that time, I spent seven years as a caretaker at the high school. I can work better with men for some reason than I can with women. I don't know what it is; I guess being a woman with autism, you have trouble getting dates. You can't do the things - and I didn't feel at home with women. As I said, I guess I responded...felt more at home playing with boys when I was very young. They weren't so catty as women. After seven years at the high school, then I put in for a transfer. I thought I needed a change, so I worked with a lady at (another location) for a year. That didn't go very well, but I still stayed at (the new location). Then I learned to do stripping and waxing on my own, which I did, and I figured, "Well, I might try to become a head caretaker". Of course, at that time, the doctors tried me without medication, because I was still gaining weight. And I was successful with that for just over a year, until I had a relapse because I failed the head caretaker interview.

Margaret: What happened with that situation?

Pam: I couldn't answer the questions that they wanted me to. I couldn't explain myself. That's when I told them that I had autism. I didn't want to tell them then. One thing about a job interview: never tell them you're disabled. They won't hire you. Another thing in job interviews: you dress neatly and you have to have a good record. One thing I did know about job interviews; if they offer you a cigarette never take it, because they won't hire you. They figure you'd smoke on the job. You have to be careful. You could ask

how much they pay an hour, what are the hours from, what kind of work you do. You don't say when your break is, how long is lunch hour...that is bad. Maybe that's why I was successful getting into companies.

Margaret: And how did you learn that, Pam?

Pam: By instinct, I guess. I learned that at the workshop. The director at the workshop taught me good work habits.

Margaret: How about now? What kinds of things do you like to do for fun, Pam?

Pam: Right now, I walk my dogs, listen to CDs, watch videos, and hang out with my friends you know.

Margaret: Yeah, and you live a pretty good life.

Pam: Yeah.

Margaret: What kinds of things do you still hope to do in your life sometime, Pam?

Pam: I'd like to fight for the people that are on ODSP (Ontario Disability Support Program) and help fight for their rights to get better money even though I'm fortunate not to be on it. And I'd like to do presentations down the road, maybe write a whole book someday.

Margaret: I hope so too, Pam.

Pam: Yeah and as I say, live one day at a time. Just do your best and try to survive.

Margaret: Exactly. Thanks a lot, Pam.

WHAT AUTISM MEANS TO ME

by Jim Deaves

I understand that you want to learn about autism.

I can share some things with you.

What autism means to me: You might think of autism as a disability, but it is more important to think of autism as having abilities. So, it's about both being able and then sometimes not being able.

How it affects my life is a difficult question. But I am more sensitive to my environment. For instance, I am more sensitive to high tone, loud sounds and noise. That is very hard on me.

Support friends can help an individual with autism by being considerate, kind and by being patient – having patience. It is important for support friends to know that sometimes within, during the moment, I get overwhelmed and that it's just one of those times or positions. In these times, together, we do deep breathing or deep breaths. Friends need to have the freedom to come into the soul spirit softly and as well with gentleness.

What I find helpful is to have a good pace to the day that I have planned and can count on. That way, I'm prepared, calm and I don't get all stressed, nervous and anxious. Also the time is flexible so I can leave whenever – then nothing gets built up.

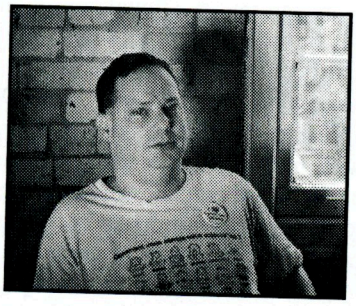
Right now, I attend Humber College where anyone and everyone can attend. I study different topics like Anthropology and Sociology and enjoy them all. Since they know me down there, I found a work job in the games room, where I was in charge of the cash and selling pop and snacks to the students.

About my interests. I enjoy tennis. It cools the stress. I work at my church and enjoy prayer gatherings. I love to swim, skate, hike and do yoga. My passion is painting, I find it soothing, relaxing. And I love all kinds of music. I keep up with friends on my email and enjoy computer games. I also love chess and belong to a chess club.

I hope my writing has been helpful to you.

CONTRADICTING THE EXPERTS: DON'T ASSUME

by John Gelmon



When you have a disability of any nature or a condition that may result in you appearing different than the average person, you are likely to be told by the so-called experts that there are a lot of things you will not be able to do. Regardless of how serious your condition is, you could have a professional such as a psychologist, psychiatrist or vocational counsellor tell you that you will never make it in a regular school class or that career options are limited. Regardless of how well you do on a Standard Achievement Test, your professional counsellor may come up with reasons why you will not succeed. Taking the negative information with a grain of salt may be the best approach.

When I was 13, I achieved an average score on my math and spelling standard achievement tests despite having a learning disability, which years later was diagnosed as Autism Spectrum Disorder. (Rather than call it a disorder I will from now on refer to it as Autism Spectrum Condition, a name that correctly implies that autism is not necessarily a disability. People with ASC, as do those with other so-called handicaps, have strengths that offset their weaknesses.)

After the school psychologist gave me my scores, I thought that she would be delivering wonderful news to my mother about my chances of transferring from a special class in a private school to a regular class in a public school. But much to my surprise, the psychologist told my mother that there was no way I could make it in a regular high school class and that I would have to go to a vocational school. According to the psychologist, the fact that I had difficulty copying designs meant that I would have too many obstacles to overcome.

It is only natural to assume that professionals are almost never wrong, but one should not be so quick to conclude that medical, educational or vocational test results have a lot of merit. After all, I managed to graduate from a regular high school program, obtain two community college diplomas (Legal Assistant and Journalism) and graduate from university with a BAA (Bachelor of Applied Arts) in Public Administration. In addition, I received five French Immersion diplomas and lived with French speaking families in Quebec. For several years, I was employed as a full-time newspaper reporter/ photographer (in spite of the fact that my vocational counsellor said I would never make it). I also have experience working in a provincial government position as a customer

service clerk for the Ontario Rental Housing Tribunal. In addition to doing a little freelance writing, photography and judging stories for the annual Toronto Star short story contest; I am a school bus driver, a position that requires a special driver's licence. Two years ago my vocational consultants and counsellors did their best to assure me that I was not fit to drive a school bus. Some were shocked that I could even drive a car, which I had been doing for the past 17 years. They felt that, due to my weaknesses in spatial perception, I should not drive. Obviously, the Ontario Ministry of Transportation does not share this view, since they are well aware of my disabilities. If you ask me, people with below-average spatial perception may actually be safer drivers than the average person on the road. Sure, having a condition such as ASC might result in you taking longer to learn to drive, but once you get used to it you may find that you have fewer problems than many drivers. You can compensate for below average spatial perception by allowing a larger following and stopping distance between cars, something far too many drivers do not do. If every driver in the world maintained as big a following distance as I do, there would be far fewer collisions.

I should also note that being a person with special needs enables me to be more patient with misbehaving students or those who take longer than average to get on and off the bus. I know that yelling or putting pressure on people can be counterproductive. School bus drivers, parents and teachers who yell at children quite often have more trouble getting them to behave than those who have a more relaxed manner. When I was 7, my school bus driver yelled at us constantly. I did not feel sorry for her then and I still do not.

Professional counsellors are going to work hard at getting you to believe that they know what they are talking about, but often, I believe, they do not have a clue. All they do is go by the book. The best way to deal with professional advice that you wish you had not heard is to use it as a challenge. Take advantage of the opportunity to do something you were told you would never be able to do.

Do not push the panic button because panicking is one of the worst things you can do. It was panic that resulted in me being enrolled in a military style boarding school for three years. The psychiatrist who recommended the school was on the school's board of governors and naturally he would promote the school, knowing full well that the parents of the children he saw were panicking and in search of a miracle solution. He told parents that disabilities were all in the mind and their children's problems were that they did not want to work hard.

This psychiatrist completely ignored the fact that I had been averaging about 90 per cent in a special class (basic level) at an English language school in Quebec. The fact that I did so well (when I could have worked half as hard and still passed) did not convince him

that I was a hard worker. I still have nightmares about the boarding school and other panic attacks that would likely be a lot worse if I were not taking Paxil.

I think it is important to encourage students to focus on their strengths. After all, everybody has strengths and weaknesses, and those who work with their strengths and compensate for their weaknesses when necessary are the ones more likely to succeed. In other words, why struggle with geometry, drafting or biology instead of taking the time to learn how to use a computer or write newspaper articles when your strengths are in the latter two areas?

I also think it is essential to allow students with disabilities extra time to write tests. Lower marks may wrongly imply that a student did not know the material well enough, when the true cause was more likely to have been insufficient accommodations, such as extra time for tests and exams. As the director of the Access Centre (for students with special needs) at Ryerson University said when I enrolled at Ryerson, giving people extra time to write tests is only allowing them extra time to apply the information they know. It is for this reason that post-secondary institutions and public high schools give students with certain conditions, such as learning disabilities, extra time to write tests and exams. The extra time I was given at university is one reason why my marks were significantly higher than before.

Interestingly, my best high school year by far was the lone one I spent at a public high school, Eastern Commerce, where I averaged 70 per cent taking Grade 12 courses at both the general and advanced level. So much for the theory that I would do better taking only advanced level classes at a strict military school.

While everybody needs to deal with pressure, it is a good idea not to overburden oneself with it. I function so much better when I am not being yelled at and am not worrying about getting into serious trouble. The same goes for many people, including those with ASC and other neurological conditions. I need to relax and have confidence. It is no coincidence, for instance, that I had trouble learning to drive a car until my instructor finally stopped yelling at me every time I made a mistake.

Having ASC or other types of learning disabilities can affect your ability to deal with pressure. Sometimes medication such as Paxil and Risperdal, both of which I take, can significantly reduce anxiety and help you complete tasks a lot faster. However, no matter what dosage your doctor says you should take; you have to experiment with different dosages until you feel comfortable. If you find that since you started taking the medication you have become drowsy more often, you should lower the dosage. By the same token, if you are having more trouble falling asleep, you should talk to your

physician and/or pharmacist about changing the dosage and the possible side effects caused by the medication. It is your responsibility to evaluate the effects of any medication you are taking, and to discuss any concerns with your doctor. Ultimately, the decision to take or discontinue any particular medication is in your hands. Although this is not always the case, lowering the dosage is sometimes a better idea than abruptly stopping a medication. Taking medication at the right time of day is also essential.

I find that the biggest aid in coping with my condition is using my strengths to my advantage. My biggest strength is my memory, which includes the ability to remember details and dates of things that happened up to about 30 years ago. I can, for instance, remember what medication I was taking, the exact dosage and what time of day it was when certain events, positive and negative, happened.

At my boarding school, the other children used to pick on me constantly until they became fascinated with my memory. Once they realized that I could remember the exact dates they experienced certain punishments and what we had for dinner on a certain date, they liked me a lot more because I was able to impress them. Twenty-two years later, I can still remember what happened at the military school on specific dates.

The best person to decide your strengths and weaknesses is you. Some people opt for vocational assessments before deciding on a career path, but as I mentioned before, vocational assessments can be misleading. There are job-finding counsellors and job coaches who help people with special needs find work, but one should use caution when working with them. I once had a job finding counsellor and job coach who works solely with adults who have an ASC diagnosis. Through a temporary employment agency, she got me a job that she guaranteed I would have for six months. Four months later, my position ended as a result of routine cutbacks. When I sued her and the temporary employment agency, she denied telling me I had a contract, but documentation I entered as evidence suggested otherwise and we settled out of court. However, the settlement was reached a few months after I was forced to go two months without an income. Thank goodness I had bank overdraft protection and credit cards I could borrow money from.

Like it or not, people with ASC have many obstacles to overcome. But as is the case with everybody else in the world, there are certain things that you are more likely to succeed at than others. Despite what professionals and other people might imply, having ASC does not make you a loser. There are things that you can do much better than other people. If you are in a situation where you feel you must tell an employer or prospective employer about your condition, never hesitate to market the strengths you possess that come with your condition. Having ASC no doubt makes you different from others, but not a less efficient individual.

MY WORLD OF AUTISM

By Darcy Gilliland

I am a person with autism. I was born at Toronto General Hospital on Monday, March 5, 1979. I have lived in Toronto all my life and I know it really well. I have also been to other cities, such as ones in Minnesota and Ottawa. I have gone to all kinds of places in my life, and I still have many more I want to see.

I live with my mother. She and my father separated in the summer of 1984, when I was five years old.

I was diagnosed with autism in 1983, when I was 4 years old. It was then that I became involved with the West End Creche. I was there until I graduated in the spring of 1985. I became involved with the Geneva Centre in the fall of 1985, and have been involved there ever since. I have met many interesting people who worked at the Geneva Centre. It is like a second home to me. I have many wonderful memories from my time there.

Autism is a disorder with several characteristics, such as: thinking differently from others, doing repetitive movements such as hand flap and rocking, having a hard time fitting in with other people, and having a world of your own. For me, being autistic means that I find it hard to fit into conversations, but think in interesting and artistic ways, and have a strong interest in music. I like every kind of music from hard rock to classical. I like many different music artists, from U2, Led Zepplin, Aerosmith, Guns N' Roses, and David Bowie, to The Beach Boys, The Beatles, The Rolling Stones, Phil Collins, and Alanis Morissette. Music is a big interest of mine.

For me, being autistic means that at times I have a hard time fitting in because I have a tendency to go into my own world, and I am not tuned in to what is going on around me. There are certain people I can relate to better than others, and those I can relate to are my truly close friends.

I have a good friend who I met in September 1998, when I started attending the adult support group at the Geneva Centre. I have had very good conversations about family and life issues with him. We have a lot in common and we like to hang out and do stuff together such as going to movies. We like to sing a lot and we both have a blast whenever we sing karaoke together. Sometimes, we just hang out together, and sometimes I hang out with him and his friends, who I have gotten to know quite well and who are beginning to become my friends.

When I was little, I would spend a lot of time on my own, isolated from other children because I didn't always know how to get involved with them. My isolation continued until the summer of 1998, when I went to Camp Kodiak and made many close friends.

A lot of autistic people have illusions in their heads about certain things, whether it is music artists, certain places, or certain people. For example, my favourite kind of music is hard rock. It makes me think of pubs because everything is lively in pubs on certain nights of the week. I also have illusions of pictures in children's books, which remind me of certain areas in downtown Toronto. I also have illusions of certain areas in downtown Toronto when I hear certain rock groups and artists.

Having autism also means that you communicate in different ways than others. Autistic people have a certain way of communicating, whether they talk really fast or really slowly, or have a hard time getting the words out of their mouth (this is something I find difficult). Autistic people can also have certain reactions to things, such as really liking or really disliking it. For example, some autistic people really like certain sounds, while others totally dislike certain sounds. Some autistic people can see certain colours in their minds when they hear certain sounds, as I do. I see autism as a birth defect. Since I am autistic, I am not yet able to be out on my own 100% without some supervision.

Due to others not understanding autism, has put me in some rough situations. In grade 9, I got picked on a lot by other boys. They would tell me to do things like getting on my hands and knees and barking like dog, and tell me to jump up and hit my head on the ceiling. This happened because there were not always teachers around in high school to look out for students. I felt like I was on my own. There were supposed to be teachers to look out for me, but they either weren't doing their jobs very well, or they really didn't know very much about autism. There were, however, other teachers who did help me a lot, sitting with me and helping me to learn.

I had another bad experience at a summer day camp when I was beat up by one of the campers. The counsellors thought that I could look after myself and didn't think I needed any special help. I think that this was because they didn't understand autism.

I have really learned a lot about autism over the years. I remember my two first caseworkers from the Geneva Centre. They really helped me understand about autism and I will always remember them for that. One of the workers came to my school in 1985 and helped me with things like math, reading and she would play with me. I have gotten to know a lot of people from the Geneva Centre over the years, and have made some good friends who I still keep in touch with. Some autistic people are a lot like me because

they like music a lot and some also have some of the same thoughts as I have. I guess that all autistic people are alike to some degree.

When I was a baby and a little boy, I had an obsession with playing with plastic letters and numbers. This is how I learned my alphabet, how to spell, how to count and how to read. I really liked the way that letters and numbers looked. Some other favourite toys of mine were little people and toy dollhouses. Those toys helped me stretch my imagination. I would imagine they were real people and real houses or places. I think this imagination helped prepare me for the real world.

I also have an interest in collecting flags of the world. I have a big collection of flags and it will continue to get bigger. The thing that really interests me in flags of the world is the symbols on them. I am very passionate about the country I live in, Canada. This is why I have such a big collection of Canadian flags, including a full-sized one in front of my house.

I also enjoy playing music and I can play a couple of musical instruments very well. I play the piano and the guitar. I have been playing the piano since 1990 and I have been playing the guitar since 1991. Playing music is fun, especially when I get the opportunity to play with or for other people. I get real joy from playing music. Due to my autism, I am a human music library. I know over 100 names of rock groups and artists. I am a music genius. I also really like music videos, and like to watch them on TV. Since I have such a strong interest in music I have a big music library of CDs and cassettes.

Another thing about me being autistic is that I have crushes on a lot of young women, such as Alanis Morissette, one of my favourite singers. I think she is one of the best pop stars of all time.

What is autism and where does it come from? I guess that will remain a big question for a long time. I have learned a lot about autism, and as the years go by I will continue to learn more. When I was diagnosed, I remember hearing the word autism for the first time and I did not even know what the word meant. Over the years I have heard a lot of different definitions of autism, from many different people, and that has helped me to understand more about it and where it comes from.

Through reading my essay I hope you have discovered my point of view about autism. Autism is like one big puzzle; we are always trying to put the pieces together to find out exactly what it is and where it comes from. I think that I have a lot to offer through my knowledge of autism and my point of view.

ASPERGER'S SYNDROME: WHAT IT IS FOR ME

by Peter Jansen

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First of all, I'd like to shed some personal insight on a few topics that are being hotly debated at the time of this writing: just what Asperger's Syndrome is, just what the autistic spectrum is, are they related, and finally, how? There's a lot of confusion and disagreement out there, and I don't think any of it is necessary, although it is justified. AS is part of a continuum of codified behaviours and mental traits that psychologists have studied and arranged into a spectrum, a range of proportions and degrees. AS is considered a "high-functioning" autism diagnosis only because the diagnosed person more closely resembles in thought, speech, and behaviour an undiagnosed person. It is not, in my opinion, a value judgment of any kind and should not construed as such. Our progress, all of us, is impeded when we start attaching to words and getting bogged down in language. Although political correctness must be a consideration as we talk about ourselves, each other, and propagate accurate information, I'm still a firm believer in calling a spade a spade. In my opinion, high-functioning people are not inherently superior human beings compared to low-functioning people; to think otherwise is a form of bigotry. Recently there has been a movement within a grassroots organization to which I belong, to amend the acronym Autistic Spectrum Disorder (ASD) to Autistic Spectrum Condition (ASC). Among the synonyms my word processor provided me with for the noun *condition* were "disease," "plight," and "affliction." Our efforts to sanitize the terminology can take us only so far before they begin to cause more confusion and wrong ideas than they were intending to correct.

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In conversation with me, Asperger's Syndrome (AS), Autistic Spectrum Disorder (ASD), or even autism would rarely, if ever, come up. Why is that? I guess the truth is clear in its obviousness: I don't think about it that much. Since AS has affected my life only mildly, I have the privilege and the luxury not to. I have the freedom from it. I don't think of myself as a person with any kind of syndrome or existing on any kind of spectrum; I'm just me. If you can pin down and colour-code what's wrong with me, fine. But I'm starting to get the feeling that, the more you concentrate, the more you bear down and zoom in on your disorder or condition or whatever you want to call it, the more it will possess you, consume you. It's an infinite regression, an unsolvable puzzle containing only an endless number of progressively smaller unsolvable puzzles, like the one of those Russian dolls. I'm willing to bet my left kidney and a good portion of my home library that the more answers you dig up, the more questions you'll be left with. You could very

well drive yourself insane looking for The Answer, The Why, The Solutions, and The Fix. Unless, of course, you want to become an expert in your field and surrender your life to autism research.

I'm lucky enough not to have my psychiatric condition dominate my life. I don't have to eat, breath, and sleep Asperger's because my life is not a constant struggle against it. In that respect I realize I'm fortunate. When the ocean is at low tide, though, the rotten pier-pilings poke through the surface, furry with barnacles, mushy with rot, and altogether revolting. In other words, AS is apparent at some times in my life but not at others, altogether miserable at some times yet completely forgettable at others. It has become so integral to my internal processes I don't even think about it as a label - never did. Does an ant know it has six legs? No, of course it doesn't. I guess it has something to do with my early age of diagnosis, which was at eight. How do you explain the autistic spectrum to an eight-year-old kid without dumbing it down into meaninglessness? I think my parents told me what I had when I was in my early teens, but that's like telling a guy who's been smoking for twenty years that he's *addicted to nicotine*. You're telling him conceptually what he already knows viscerally, experientially, outside the mode of language.

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I realize that my parents were extremely hesitant with me as a child, resulting in the withholding of information. They were wise. Treatment and several different therapies, assessments, and tests had begun long before I was old enough to understand what was going on. In hindsight, would it have been better to tell a kid that he's different from all the other kids in school right off the bat, to really instil that concept in his head whether he wanted it or not, rather than letting him figure that out for himself? I think the way I was handled as a child was very skillful. I had a lot of good teachers. Special programs were available to me throughout elementary and secondary education, at St. Mark Catholic School and Loyola Catholic Secondary School respectively, both in Mississauga, Ontario, although the programs were deigned specifically for a mildly autistic child. However, there were only so many concessions an educational system that didn't understand AS could make. More than a few times I had difficulty with schoolwork. This was due to my serious difficulties with organization, which persists to this day. Most of the teachers in elementary school didn't understand, got frustrated, and couldn't figure out why I didn't complete the assignments when I had ample time. Also, my diagnosis was most apparent on the playground, where I didn't socialize with anyone else but simply wandered around until recess was over. Not because I consciously didn't want to, but because I simply had no one to chum around with. I've always thought of myself as just DIFFERENT. A human being of any intelligence can discern when and where he deviates from the herd. Just the cognizance of being DIFFERENT is enough

psychological baggage for me, folks. I'm too busy trying to live my life, trying to blend in with the other homo saps as best I can. I can talk about it and write about it, sure, but I'd rather not turn it into an obsession, because I'm not entirely comfortable with it. At times it unsettles me, the talk of it, if you must know. I recoil. I cringe. I hate what I fear; therefore I hate what I am, if only in part and at the deepest psychological level. But the consolation lies in knowing that I'm THE SAME in all ways that really matter. There's only a slight difference between the words "same" and sane," but there can exist universes in between the two mental states. Isn't it amusing how those who are fundamentally THE SAME would practically commit *hara kiri* to convince you they're essentially DIFFERENT, while those who are truly unique would give anything to be THE SAME? We have DIFFERENT clothing styles, DIFFERENT music styles, DIFFERENT special interests, DIFFERENT cliques of DIFFERENT people engaged in DIFFERENT activities that, above all else, refuse, resist and fear conformity.

Underneath all this camouflage, I think you'll find all these people are THE SAME. Those who are truly DIFFERENT may stand out for the wrong reasons, reasons they themselves were not privy to, or simply not stand out at all. I offer myself as an example: I could pass unnoticed through just about any North American crowd. If I told you I was once diagnosed (incorrectly) with Bipolar Disorder, once confined in the Special Care Unit at a hospital's Psychiatric Unit, that I was borderline autistic, that I am a tenderfoot Buddhist and suffer from acute depression and loneliness, anxiety, panic, *would you be able to pick me out of the crowd at Square One Bus Terminal?* No, because of your preconceptions after having received all that data. Things are not always as they appear to be.

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I'm undergoing a very painful, very awkward stage in my life right now as a young adult with AS mainly for the two reasons I've cited above. The First Law of Psychology states **things are not always as they appear**, and that law can work in both directions. I've been around people like me long enough to be able to know what to look for; I can spot an ASD person with relative ease. Where I get burned is when people, analyzing my behaviour and appearance, overestimate what I'm capable of, whether at work, school, or in a social setting. They simply have no way of knowing just what my deficiencies are because I'm never forthcoming in that regard. Who would be? On the other hand, one of the most terrible blows to my self-esteem is patronization, being treated like a child, a dependant. Seemingly, unshakeable is the belief in parents, caregivers, and service providers that I'm a child in an adult body. It's very strange and awful, the inability to decide in your own mind whether you're a boy or a man, or something in between, an ambiguous both-and-neither. There was a legend of a boy who never grew up, one who

shares my name, but unlike him, I *want* to grow up. I want to do that more than anything else. But I know that building all the necessary roads and overpasses is going to be a long and painful process, because I know there's something all the 24-year-old guys have that I've missed, something I'll never get back. I'd say at this stage in my life, I'm still dealing with the acceptance of whom and what I am. And just like everyone else, autistic or otherwise, I've to find my place in this world. I've got to wrestle with this colossal and potentially crushing question of WHY AM I HERE?

MY ASD AND I

by David Maloney

The idea that "words create perceptions" has been in existence for quite some time. Moreover, for people with disabilities, there have been many different terms with a variety of connotations attached to them that have become somewhat archaic and, in some cases, offensive. As a person with an Autism Spectrum Disorder (ASD), I have for more than three years now been advocating for proper language use in the media. It is the language they use that creates the perception of us as being either extremely incapable of living productively or as heroes who have overcome massive obstacles to get to where we are today. It is my hope in this article to enlighten you about people with ASD.

GROWING UP WITH MY ASD

While I was growing up, I encountered a multitude of problems because of my diagnosis of Asperger's Syndrome (AS). For example, while attending school, I would often participate in class and isolate myself during recess. In his diagnostic criteria, Dr. S. stated that a person with AS must lead a somewhat noticeable solitary lifestyle. While I did have friends during my childhood, these people were friends of the family. I did not have any friends my own age. In fact, during my recess time, I entertained myself by playing alone or using different toys alone. It was because of my disability that I did extremely well in my studies. I would often work most of the evening away at them. Furthermore, in my senior year, I was elected to the first student council because of my genuine and caring personality. Upon receiving the news of having been elected to this position, I was ecstatic. For the most part, my disability manifested in a lack of desire for social relations among my peers.

For the most part, my teachers were consummate professionals, always trying to help me and the other students. In fact, my first Special Education Teacher was the kindest, gentlest person I ever met. After she retired, there was another teacher who was kind enough to help me learn to tie my laces. I continue to use this technique to this day. There were other teachers who, because they were dealing with more difficult students, were not as good, simply because of the pressure they were under. I generally kept to myself, avoiding my fellow classmates. My anti-social behaviour has continued to plague me throughout my life. The only other problems were my concept of what was or was not appropriate to say. When I was in my senior years, for example, I would often ask totally inappropriate questions about other people's scientific projects regarding animal reproduction.

My time in high school provided me with a plethora of experiences, both positive and negative. One of the positive experiences was meeting a Resource Room teacher. She helped me immensely by allowing me extra time to complete tests and assignments. It was because of my time with her that I was so very successful in school. I was also very pro-socially active, but once again, thanks to a minority of irritating classmates, I continued to have problems socializing. In fact, it became so difficult for me to interact with other people my own age that I would, on my lunchtime, actively seek out places where I could eat in peace and quiet. When my father heard about this, he tried to deter me from doing it, but it was ultimately up to me to decide where I wanted to eat. However, I had my fair share of positive experiences. Some of them were the various honours I garnered, while others included getting consistently high grades due my work habits.

I love to help others. I have, over the years, assisted with a multitude of events. Speaking in general terms, helping others without the expectation of an extrinsic reward is called pro-social behaviour. It must be noted that this is not altruistic, as the concept of altruism is that you do not get any kind of intrinsic or extrinsic reward.

I participated in groups such as *Newman Helps*, soliciting funds for non-profit endeavours such as class trips and volunteering my time at the Toronto Daily Bread Food Bank. I was also very active in the community through different school activities such as Scar Trek, an annual event whereby all of student body plus faculty engaged in a lengthy "trek" in order to raise funds for our school. I also worked alongside my father, helping at the Malvern Family Resource Centre and at West Hill Community Services. Throughout my life, I have continued to assist other organizations such as Crohn's and Colitis Foundation of Canada, by volunteering at M&M's annual charitable event. I have also worked at the Sports Celebrities Fundraiser, packing boxes and delivering products. To this very day, I continue to help as many people as I can.

Even more recently, I have been volunteering at the Asperger's Society of Ontario, co-coordinating social events. I really think that people with AS should have a network of support, so that they know they are not alone in their disability. I have been involved in the planning and implementation of our monthly gatherings.

In high school, I was afforded the opportunity to work for three different organizations. My first job was the best I ever had. I learned to work as a Dietary Aide, helping to prepare meals and wash dishes. Here I received nothing but praise for my hard work and positive personality. I felt that I was treated quite well at this job and that I had no disability at all.

At my second job, I worked on preparing the files for downloading during amalgamation. I would ensure that all of the information was correct so that legal files could be transferred to the new office after amalgamation. It should be noted that when my supervisor gave me other tasks that I was not adequately prepared for, I would often encounter difficulty. While I did not enjoy the concept of working at a desk with papers, I did enjoy the experience I gained from it.

Finally, in my third position, I was given an enjoyable opportunity to work as a recreationist with seniors. I assisted in various programs, and as my experience grew, I led some of them.

It must be noted that, up until I entered college I was classified as "learning disabled." I had no idea that my disability fell on the autism spectrum. I did not even know that autism even existed, though it took merely one night to change all of that. While watching a news program with my father, I learned about a disability known as Asperger's Syndrome. It seemed interesting, so I continued to watch. After that groundbreaking event, I was later diagnosed. This was somewhere between September 1997 and August 1998.

During my educational career at Centennial College, my disability continued to be a problem. I continued to have difficulty forming social relationships. I was fortunate enough to have a friend who seemed to like the same things I did, but social problems continued to plague me. For example, I was working hard in one of the computer labs one day, only to be kicked out by some professor who told everyone that there was a class going on. I felt rather offended, as this person did not apologize for his rather autocratic tone. The week after, I saw him talking to a student in the hall and was so outraged that I went between the two of them. I later apologized to the professor and left it at that. I was quite angry that day at myself. Also, it was rather difficult for me to engage in group work, as most of my partners tended to be autocratic, aloof, or irresponsible.

In my second semester, I found someone with whom I could socialize. She was very kind and I enjoyed talking to her, but my work came first. Sometimes, the workload was so much that I had difficulty sleeping at night. I found the pressure to be rather extreme but eventually got used to it.

In my second semester, I was on a co-op placement at a retirement centre. I enjoyed my time there, as I was in charge of my own recreation program, which gave me ample experience in planning my own programs. I was also fortunate enough to run a one-to-one program, whereby I would spend some time with residents in their rooms. I learned much about the various lifestyles that seniors tend to live. I thoroughly enjoyed it. Having

stated my enjoyment of that particular job placement, I still had a problem with using highly advanced vocabulary, which sometimes made it difficult for other people to understand me.

At another co-op placement, my disability was much more problematic. There I would often say the wrong thing, thereby getting myself into trouble. For example, I would use in-class terminology to discuss different things, which would offend the residents. However, I did manage to overcome my problems and eventually finished my placement.

HOW TO HELP REMOVE BARRIERS FOR EDUCATED AND EMPLOYABLE INDIVIDUALS WITH ASD

During my educational career, I was quite fortunate to not encounter many barriers. My employment history is another story.

EDUCATION: BARRIERS AND STRATEGIES THAT PEOPLE WITH ASD CAN USE TO OVERCOME THEM

Some of the barriers that people with ASD will encounter during their education will be quite unique. On the other hand, some of those same barriers people with ASD can encounter are widespread across the entire autism spectrum. For example, while I was going to school, I would often have difficulty engaging in social interaction. I believe that early intervention is necessary so that children can learn to interact socially. I feel that if children are taught how to interact in a social environment, they will be quite adept at doing such during recess and would therefore be able to adjust to the notion of recess and develop normal social interactions.

Another potential problem for children with ASD is their insensitivity to others, manifested in inappropriate speech. For example, the child should learn to not say certain things. Parents must sit down with the child as needed and discuss with them what is appropriate to say and what is not appropriate to say. Parents should also speak to the child's teacher to learn if all is well in class. The child's behaviour during various activities such as school trips, recess and lunch should also be discussed.

If the child is experiencing serious difficulties, there are several resources available, including the Geneva Centre for Autism, The Asperger's Society of Ontario, Autism Society Ontario and others that have a focus on disabilities in the autism spectrum.

IMPEDIMENTS TO SUCCESSFUL EMPLOYMENT AND HOW TO OVERCOME THEM

As I have stated earlier, the idea that words create perceptions is quite well documented. It is through what the person with ASD knows and has experienced about his or her personal ASD that creates the perception of being unemployable. For example, drawing on my experience at college, I had little to no clue what problems my disability caused for me. Had I had known this; I would have been able to represent myself much better as I could explain the supports that I needed. I feel that it is imperative that once the person is diagnosed, they gather as much information about their specific disability as possible. If you, dear reader, learned that you had an ASD, would you not desire to know as much as possible about it? Or if a loved one were born with an ASD, would you want to go to the nearest library and read about the ASD until there was no more to read?

Another barrier people with ASD encounter include their own behaviour. It is my belief that if someone with ASD becomes comfortable with their lifestyle, they may become stagnant because of the tendency to maintain certain routines, whether or not those routines are functional. It should be noted that one of the diagnostic criteria for AS is adherence to non-functional routines. I feel that if a person with ASD is always doing something, they will never become stagnant, with the individual succeeding in ways the parents may never imagine.

One last barrier is the perception of the public. The general public is becoming more enlightened about ASD, but their perception is skewed because of what they tend to see on the news and on other TV shows. It is the media who must be taught to use the proper language when talking about us. There are, however, some TV shows that show ASD in a positive light. It is critical that these shows continue to be created, as they are essential in helping the public arrive at a more accurate perception of people with disabilities.

COMMUNITY ACCESS AND PARTICIPATION: WHAT MUST BE DONE TO TAKE DOWN THE BARRIERS

Access to community is very important to people with ASD. Barriers faced by people with ASD include family, quality of life, work, and personal relationships.

BARRIER NUMBER ONE: FAMILY

I have been fortunate. My family has not been a barrier for me, but that is not true for all people with ASD. One person with ASD that I know is currently unemployed and has not been able to find any kind of work for himself. I have been trying to help that person find

work, but to no avail. In another family, the parents of the individual with ASD are currently unemployed and that person has been fired from his job because of baseless allegations that I will not divulge here.

Dysfunctional family situations can hinder the development of the person with ASD. Imagine an alcoholic or drug-addicted parent who is abusive, for example. A child with ASD in such a family will have even greater problems adjusting to normal life. However, for the most part, I find most families of people diagnosed with ASD to be kind, supportive, and as helpful as possible.

BARRIER NUMBER TWO: QUALITY OF LIFE

The quality of life for an individual with ASD can be adversely affected by certain factors such as social status, wealth, and family. Factors include whether or not the individual lives alone and where they work.

I use the term social status to denote what kind of a social life a person has. For example, many young adults with ASD avoid dating simply because of their lack of social skills, coupled with a desire to be alone or an avoidance of social situations. In more classical cases of autism the person may not be able to function socially at all.

Wealth can play a tremendous role in terms of the person's quality of life. If the child comes from an underprivileged family, that child may strive to improve him or herself so as to help his or her parents rise above the child's perceived notions of the kind of life the family leads. If the child is from a privileged family, then they may try to help others with other forms of ASD.

BARRIER NUMBER THREE: WORK

Work can be an obstacle for people with ASD. This is why some people are unable to find work that they enjoy, floating from job to job to job. I am working with three different organizations right now. It has been difficult for me simply because of my disability, which causes me to speak in inappropriate ways. I have learned to control this tendency thanks to my job coaches. However, some people diagnosed with ASD that I know are not currently working, and I have been trying to help find them work.

BARRIER NUMBER FOUR: PERSONAL RELATIONSHIPS

Personal relationships can be problematic for people with ASD. For example, I have often had difficulty developing and maintaining personal relationships, as many of the

people I know do not speak to me often. Sometimes people either move away or transfer to another job. Many of the people with AS that I know are not romantically linked because of their lack of desire or inability to engage in social activities. In my opinion, some people with ASD often cannot distinguish between platonic and romantic relationships. My father has expressed concern that I will remain a bachelor. While I cannot be certain of that at this point in my life, it certainly seems like a possibility.

CURRENT SERVICES AVAILABLE TO PEOPLE WITH ASD

There is a plethora of organizations and individuals offering services to people with ASD.

SERVICE AREA ONE: NON-PROFIT ORGANIZATIONS

There are all kinds of organizations devoted to people with ASD. For AS alone there are currently two organizations devoted to helping people with that disability: The Asperger's Society of Ontario (website: www.Asperger's.ca) and Mission Possible (website: www.anythingispossible.ca), an employment agency run for people with AS. I am proud to say that I have been involved in each organization, one as a client, and the other as a staff person. As a Voluntary Social Director for the Asperger's Society, it is my responsibility to assist Margot, the President, with the running of the adult social group and complete whatever tasks she assigns to me. I have continued to enjoy helping people with my disability as I have been trained in recreational services.

There are other organizations devoted to people with ASD. For example, I am a client of The Geneva Centre for Autism (website: www.autism.net) in terms of being part of their social group. I found that the person in charge, Mr. W, to be a consummate professional in what he did. I have been quite impressed with the multitude of services they offer to all sorts of individuals and organizations.

SERVICE AREA TWO: ONLINE SERVICES

There are few strictly internet-based organizations devoted to people with ASD that I know. The Online Asperger's Syndrome Information and Support (OASIS) (website: www.udel.edu/bkirby/Asperger's/) is one of them. They offer links to other organizations, publications about AS, and have a message board so that people can talk about the disability. Though I do not use OASIS often, it has been of great help to me. It provided me with the documents I needed to prove my need for financial support from the provincial government.

SERVICE AREA FOUR: THE GOVERNMENT

I have had pleasant experiences with the provincial government. First, I have fortunate enough to be part of the Ontario Disability Support Program (ODSP). In it there are two distinct parts: Financial and Employment Support. Once the panel approved me for Financial Support, I then proceeded to apply for Employment Support. I have benefited greatly by accessing ODSP Employment Support. I now have a job thanks to their excellent efforts. They provided me with the necessary supports so that I could work as a shipper and receiver.

HOW YOU AS EDUCATORS CAN HELP US

It is my opinion that words create perceptions. Fortunately, though through people like my father, people can be educated to speak with more respect for people with disabilities. My father is a principal and works with teachers, parents and children. He has been an excellent educator and administrator in his thirty plus years with the Toronto Catholic District School Board. Having him as a father was very good. He was able over the years to help me get the proper schooling and teachers I needed. So in order to be professional in your work as an educator for your staff and for yourselves, you must be educated. In my year in the Catholic school system, I found teachers who would try their hardest to educate me. For example, you must be willing to help us by taking your staff aside and telling them about the client. You also must know the proper language for working with us. I have found that many professionals in the disability world to be quite uneducated about proper language. For example, I am in current ownership of a book called *A Way With Words and Images*. In it you would find the appropriate way to talk about us. For example, it states that you should not refer to someone as disabled but as a person with a disability. It is available from 1-800-CANADA. Also, it is imperative that as an educator, you try to provide the best services available to us. That can vary from applying for specific government services to providing medication. For example, it was through my experience in the field of autism that I am currently able to assist a young adult much like myself, try to get a career in his chosen profession, zoology.

I also feel that as educators, you should try to improve yourselves by reviewing up-to-date articles and consultation with various special interest organizations like Asperger's Society and the Geneva Centre.

HOW YOU AS PARENTS CAN HELP US

As a parent, my father always did his best to help me. As parents or relatives, you have a tremendous role in a child's upbringing. When I was young I was frequently picked on and bullied because of my talents. While I was able to get through it using different techniques such as avoidance of others, it is imperative as the parents that you try to instil in your offspring a sense of respect for children with disabilities. Much of the time people like myself are not properly diagnosed and are viewed as being "odd" and "nerdy." Furthermore, parents should try to help a child by exposing him or her to a variety of people with disabilities. I was exposed to disability at a very young age and am glad of it. I was in Variety Village, a premier facility for athletes with disabilities. There I saw all sorts of people: one person missing a limb, another had gait problems. After all, people with disabilities are not merely people in a wheelchair. They are our Olympians, teachers, and successful entrepreneurs. I think that, in order to help, parents must try to be kind and tolerant of other people with disabilities as are people too.

Further to this heading, you should try to educate your children on what disability is. You should try to engage them in what they think the word 'disability' means. For me, it means all sorts of things. But that is because of my experience in working in different seniors' residences. I met seniors with heart problems, cognitive disabilities, physical disabilities, visual and auditory disabilities. You should also encourage a child to spend some time with a senior. I think the experience would be invaluable. After all, everyone grows old, and we should respect the aging process, as here is where anyone could develop a disability.

HOW YOU AS INDIVIDUALS WORKING WITH PEOPLE WITH DISABILITIES CAN HELP US

Speaking for myself, I have had much support over the years. But speaking for others, it is crucial that a person grows up in a supportive environment and be provided with the best supports possible. For some it may mean working one-on-one with a special education teacher. For others, it may mean getting extra help with their schoolwork. It depends on the individual. I think that in order to help any given person with a disability, you must first explore the services that are out there to help us.

The prime example as of available services for people like myself would be the Metro Toronto Association of Community Living (TACL). These people help anyone with a disability adjust to new surroundings. For example, I know a person who is legally blind. This person uses the CNIB to help himself in different ways. But TACL has helped him by providing him with ways to live a normal lifestyle, from lining his floor with a special

kind of tape so he can try to make his way to different locations. He also has different devices at his disposal such as a tape player with books on tape to a cane and a walker and other practical items that help him live a normal life.

HOPE FOR THE FUTURE

It is my hope that, through various organizations, we will be able to expand awareness so that a whole network of ASD organizations will develop throughout Canada. I feel quite strongly that it is through support and networking that a national awareness of our disability can emerge. Right now, the only province-wide organization is Asperger's Society of Ontario [that responds exclusively to Asperger's Syndrome]*. I hope to see similar organizations in each province and territory, with a national headquarters. I also feel that if each provincial government had disability services like ODSP, many of us would become valued contributors to society.

**Editor's note: There are several organizations with a province-wide mandate that respond to issues and services relating to Autism Spectrum Disorders. Their role and scope of services within Ontario vary.*

THE PERILS OF THEORETICAL BASKETBALL

by Vern Nicholson

I would like to reflect on my experiences in childhood, adolescence and adulthood and share a few modest insights that I have gained in light of my newfound awareness of myself as a person on the autism spectrum. I hope that my perspective enables the reader to further appreciate some of the challenges and strengths inherent in the autistic experience.

Childhood

I have trouble remembering much from my childhood. Having said that, I knew that I was different early on, but life was relatively serene. I had no major problems until adolescence. No one knew or suspected that I was on the autism spectrum, including me.

I can share a few memories with you. I began reading newspapers at the age of two. At about the same age I was attracted to drawing car and gas station logos. To this day, I have a fascination with logos, typefaces and design in general: on CD and book covers, billboards, and especially street signs. Later in childhood I became immersed in astronomy, followed by maps, then music.

I had trouble differentiating between literal and implied meanings. My parents had asked me "do you want a cookie" enough times that I must have concluded that my new name was "you." So when the hunger pangs struck, I would insistently declaim, "You want a cookie!" My parents would ask if "you" wanted to "go down the street" to play with friends and were most puzzled to find me walking straight down the middle of the road. Here's another one: when I started baking oatmeal cookies, the directions on the box insisted that I *butter the bottom of the pan.* Though I didn't quite understand how that would help the cookies bake, I obediently flipped the pan over and generously layered the underside with butter. These and other such misunderstandings were innocent enough, but when asked at twelve if I was *gay* and, assuming that word meant *happy*, I said yes, my peers were not so forgiving. Their laughter meant something quite different than the laughter of my parents over my baking escapades.

In school I was quiet, studious, and had little interest in athletic activities, childhood games, or having friends. I was not completely socially isolated—that would come soon enough—but I didn't really care whether I had friends or not. I was introspective and

drawn far more to my inner world than the outer world. In grade school, my teachers reported that I was bright but prone to daydreaming.

I also had problems with my physical coordination. I recall having a tough time learning to tie my shoelaces. Only after relentless prodding from my parents did I learn how to swim and ride a bicycle. I was awkward and unskilled in gym class. Even my gait was considered rather odd. These days, though my coordination is smoother, I still have trouble with certain aspects of the physical world, such as spatial perception.

Adolescence

The real action took place here, not in my childhood. Much of what I struggle with now can be traced back to that time. Seemingly out of nowhere, once I hit elementary school, I was ostracized and bullied. I suddenly realized that I was different from my peers. Girls who seemed to like me the previous year now shunned me—not that I could tell whether or not they ever really *liked* me in the first place or what it meant if someone *liked* you. Awkward, embryonic attempts at dating inevitably ended in disaster. I began to withdraw and experience depression for the first time.

By the time I reached high school, the taunting had abated, but its effects lingered. I experienced an emotional shutdown that I can trace back to a single, monumental event, the proverbial straw that broke the camel's back: after an especially vicious rejection at an end-of-year dance in Grade 8, I made a conscious decision to stop trying socially and not let *anyone* hurt me—and I meant it. Though it was an extreme measure, I maintain to this day that, in context, it *was* a rational decision. I had to stop the bleeding by any means necessary; this was the only way I knew how.

Consequently, in high school I was like a robot, out of touch with my emotions, only able to dive into my schoolwork, churn out endless A's, and lose myself in my short wave radio—my newfound passion and, not surprisingly, a solitary activity. To this day I have no idea what kind of non-verbal message I was putting across to my classmates, but I surmise that it must have been akin to having KEEP OUT stamped on my forehead. It worked; they all did, and though as a result I had no positive social encounters whatsoever in high school, I also gave them no opportunity to hurt me, and at the time, that was all that mattered.

Adulthood

It is beyond the scope of this talk to continue with the chronology and tell you about my early adulthood, where further germane developments took place. Suffice it to say that it

has been a long, slow journey from where I was in high school to where I am now. So, who am I now? Many of my autistic "symptoms" are not as pronounced in me now as they were in my youth. However, I still feel persistently different from those around me. Adulthood has brought with it a keener awareness of the difficulties and obstacles I face, but the solutions are as elusive as ever, and there is an overriding feeling of lagging well behind my peers. I am coping with the same issues that first presented themselves to me during adolescence. The issues that I grapple with—living independently, establishing a secure financial and occupational footing, and finding a suitable relationship—are more common to those in their late teens and early twenties than to people my age.

As an adult, I have learned to suppress or hide what, to me, are important but clearly unusual aspects of my personality. Interestingly, as I read that sentence, I realize anew that on a subtle level, I am still carrying out my mission from Grade 8, and I notice the same set of pros and cons. On the plus side, people have fewer opportunities to hurt me. It keeps the bullies away. On the negative side, I have internalized these feelings of inadequacy so thoroughly that I do not feel comfortable with my true self. I am afraid to let anyone know the "real" me for fear of rejection.

In contrast to my earlier years, I am now able to get along reasonably well in the everyday social world. I still experience some degree of anxiety in certain types of social situations, but I've experienced no major disasters, perhaps because I studiously avoid those situations where I know I do not do well. Some aspects of social discourse remain puzzling and ambiguous to me. It all flies by so fast, and on so many levels, that I can't properly process it. In addition, I continue to discover gaps in my social knowledge and vocabulary resulting from living a self-imposed, sheltered life. But I've learned enough to fake my way through it without any major fallout.

Life on Earth

I wish I could have been given some inside information that would have helped me to get along better in the slippery social world that you earthlings inhabit. (For those of you who don't get the reference, it has been said that autistic people often feel like visitors from another planet, busily trying to acclimatize themselves to these strange earth customs). Anyway, for most people, these gems of wisdom that I'm about to discuss are apparently truisms, not mysterious secrets; however, they have been incomprehensible to me for years. Even though I have finally started piecing them together intellectually, I still have much trouble putting them into practice. I mull over these enigmatic secrets in the same way that some of you might contemplate the profound mysteries of religion and philosophy. Bear with me while I share a few of my "discoveries" about life on planet earth with you, things that many of you have probably known intuitively since grade school:

It's Useful to Have Friends. First of all, it brings joy and comfort to associate with individuals who share, at least to some degree, your outlook on the world. Having friends helps to alleviate loneliness. Also, belonging to a social circle increases your chances of meeting potential partners, or so I've heard. However, most importantly, I have learned that if you have *no* friends, people infer all sorts of nasty things about you and react accordingly by pushing you away.

It's Important to Feel Good About Yourself and the World. One of my therapists once gave me a great quote: "Optimists and pessimists are both right about half the time, but optimists have more fun." I am not an optimist by nature, and I continue to struggle with this one. However, I have come to believe that the crucial difference between the good days and bad days lies not in the lack of cloud cover in your outer world, but the amount of sunshine in your inner world. So I actively try to cultivate good days by lighting the lamp in my own mind and letting it shine outward from there. It's not easy to do.

Confidence Is the Expressway to Success. If you are going to develop one trait and only one trait, this is the one. Apparently, one "projects" confidence—or not—and most people can somehow sense the degree of confidence a person has in themselves. And, once this level of confidence has been assessed, you are treated accordingly, particularly in certain types of social situations. As far as I have been able to tell, confidence is a universally attractive, highly desirable trait. Or, as one therapist told me quite succinctly once, "neediness is not a virtue." For me, confidence is still an elusive quality. I've flirted with it now and then, but I don't know how to make it stick around and work for me.

First Impressions and Appearances Count, Big Time. As a child, I had no idea that the clothes I wore made any kind of statement whatsoever. I now know that my clothing choices *definitely* made a statement, and unfortunately for me, it was the wrong one. I am now learning how to dress in a way that is both socially acceptable and an expression of my emerging individual style. I've learned that dress and appearance convey many things: group membership, attitudes, social class, personality, and so on. To make matters even more complex, dress and appearance can also interact with the confidence thing. A friend of mine once told me that truly confident people can get away with wearing *anything*. Armed with all this information, I still don't quite know how I want to dress at times, but at least now I understand why the fashion industry exists.

Life Is Ultimately Practice, Not Theory. As a person who tries to make sense of the world through the fanciful constructions of his own mind, this one hit me particularly hard. I have come to realize that often there are no clear, linear pathways from A to B to C, and certainly none that can be taken via the mind only. There's no step-by-step instruction manual for life and particularly relationships. One has to get out there and *do* in order to make any progress. It's no accident that, in my unending quest to figure out how to successfully interact with earth people, I majored in psychology and sociology in university. I learned a lot about these academic disciplines, and much of it was quite interesting, but I must confess that I *didn't* learn a lot about life on earth and my place in it, which, after all, was my goal. This high comfort level with theory and utter bewilderment with practice has been an underlying theme in my life. Allow me to illustrate using a sports metaphor. It's as if, for years, I've been trying to learn how to play basketball by poring over endless volumes about the rules and strategy of the game. I became quite good at theoretical basketball, but until I stepped on the court, dribbled the ball, and took my first shot, I did not even *begin* to learn how to play basketball. At some point, you have to put down the books and get out there and play. This is easier said than done for me, and I continually have to re-focus my efforts in this direction. I still think too much and do too little. After all these years, I feel like I remain on the sidelines, watching earthlings play basketball, too afraid and unsure to participate myself.

Now that I've taken you on this exciting voyage of discovery—wasn't that fun—let me bring you back to the whole point of this exercise: *These* are the kinds of things that I wish I had learned, formally or otherwise, in school. I stumbled through my youth not knowing any of this. It is my wish that all young people on the autism spectrum could learn to apply insights such as these, as well as many others that I'm quite sure I haven't yet discovered.

Vern Nicholson is an adult on the autism spectrum, living independently in downtown Toronto. He was diagnosed with Asperger's Syndrome in 2002. Since then, he has spoken to groups of parents, educators and health professionals, interweaving personal anecdotes with original insights about life on the spectrum. His passions include travel, home recording, writing, urban issues, sustainable transportation, and the Toronto Argonauts. Vern has an MA in Sociology from York University and is currently working on his first book and debut CD

MY LIFE AND TIMES

by Hartley Sigal

I was born in 1973 after a difficult delivery and at 3 years of age, I was not talking (now I never stop) so I was tested and assessed for many years at Sick Kids Hospital. As a result I was in extensive speech therapy, sensory and occupational therapy.

In pre-school, I went to Bayview Glen Nursery school, and then on to Adventure Place in the afternoons and went to morning kindergarten at our local public school. The other kids teased me because I always walked around and talked to myself, flapped my arms like I was going to fly. They couldn't understand my speech because I had very poor articulation. Maybe the other kids at school would have been more accepting of me, if they had understood my disability.

In 1988, I graduated from Ledbury Park EMS. At Ledbury, when I had teachers who understood my needs I was successful, but not everyone understood and I did have some difficult times. In elementary school, I was in a self-contained program for 3 years and continued in regular classes with support help from excellent Spec. Ed teachers.

In 1993, I graduated Sir Sanford Fleming Secondary School in North York. (Our local high school where my older brother and sister attended – I was determined to be as successful as they had been in school). I enjoyed my years at Fleming and was very successful because of the support I received from the Special Education Department even though they had never experienced a student with my disability before. I was always motivated in school by subjects that I liked and enjoyed learning about. They offered my parents and me a special timetable in grade 9 with Special Education. classes. I was able to eventually do 3 regular courses and one Special Education class a semester. During Grade 13, I did a co-op placement at the North York Board of Education in their mail department for the first semester. In the second semester, I went to a special video course called "Multi-Vid" where I learned about videography, media English and assisted an A.V. technician in different schools. This program increased my interest in photography and to this day, I am an avid photographer. At Fleming, I received a Business award for 8 credits in Typing, Accounting and Computers. I also received the Co-op award for best student in all Co-op programs that year.

In 1997, I graduated from Seneca College with a degree in Microcomputer Accounting. At Seneca, I received assistance from the special needs department with accommodations for longer test periods and organizational skills. At Seneca, I also took Computer, Business and General Ed. courses as part of my program.

In the spring of 1997, I heard Gail speak to our adult support group about her employment service "Mission Possible", which helps young adults with autism (PDD) find jobs. It was through her service that I was able to find a job. My parents hired Gail to assess me and direct me. We worked together for a few weeks, so that she would find out what my strengths were and pursue a job search from there.

In 1997, I was hired by Symcor (the Royal Bank mail department). It was my first and only interview. They hired me immediately for 2 hours a day from 7:00 a.m. to 9:00 a.m. My hours gradually increased as they became comfortable with my abilities (and disabilities). I now work full time from 8:00 a.m. to 4:00 p.m. When I first started at the Royal Bank, I was interviewed for the CITY TV news to describe my job and tell how I got to be working there. It was aired on the 11:00 p.m. news that same evening. I was nervous and only let my mother tell my brother and sister to watch. I was also written up in a magazine called "Abilities". The article was about employment and it was called WORKING ASSETS – On The Job with Autism. It described my strong memory skills; I never forget anything – a date, a place, and time.

In January 2004, I completed 6 and a half years of successfully working full time at Symcor in the Royal Bank Plaza and Bank of Montreal Mailrooms. My job is sorting and delivering mail throughout the building. It is a job that requires speed and efficiency, and makes me stay focused.

All my employers (past and present) always appreciated my punctuality and perfect attendance record. Even during severe storms (TTC shutdown and strike), I was able to get myself to work every day. At Symcor, I have received 4 attendance awards – I never missed a day. During the summers while I attended Seneca, I had part-time jobs that helped prepare me for the work world.

Outside of work, I volunteer at the Geneva Centre in an adult support group and do office work. I also attend an adult support group where we discuss our problems and topics of interest.

As a kid, I took skating lessons (tried to play hockey), swimming lessons and piano lessons. I played on a softball team – my father and brother were coaches. I was a Cub and Boy Scout for about 10 years.

I am extremely interested, as a spectator, in all sporting events. I am a true blue fan of the Blue Jays and Raptors, but I also go to the Argos, Maple Leafs and all other sporting events that come to Toronto. I have probably not missed too many sporting activities from TO to many different cities.

I have been lucky enough to travel to many events throughout Canada and the United States. Often I research and help my Dad plan these trips. I have ordered tickets over the Internet, booked hotel reservations and used computer programs to prepare maps. I have an extensive collection of lapel pins (on corkboards) and sports books. During the last 10 years, I have taken a baseball lecture course at Seneca. It takes place every Saturday morning from January to March.

Over the years, I have been involved in different support groups that have been recommended by my doctor. I went to a group at Integra, Hospital for Sick Children and now the Geneva Centre.

My most serious disability right now is my fine motor skills, which affects my handwriting. Fortunately, I have a computer and I am very good at using it. I also used the computer all through school and college.

From my early years (9 years of age), I started going to summer camp and those were some of my happiest times. I continued going to camp until I was17. It was great! I truly miss those days.

I am proud of my success, independence and all my accomplishments over the years. I have had a lot of support from my family. My parents, my sister and brother, and also my grandparents were always there for me – whether I was good or not so good.

Medication has helped control my behaviour and mood swings (temper). I have been on meds for many years (the doctor has tried different types, until we found some that were effective). They help me focus at work, concentrate on what I am doing, and be more sociable.

I am independent getting to and from work on the TTC subway and bus. (I know my way around the whole city of Toronto). I am a responsible person and look after all of my obligations and commitments. I am considered a caring and conscientious person, who is interested in everyone's well being. In the future, I hope to be able to live independently in an apartment.

STILTED RAINBOW

THE STORY OF MY LIFE ON THE AUTISTIC SPECTRUM AND A GENDER IDENTITY CONFLICT

by Martine Stonehouse

In 2001, I wrote an autobiography of my life titled "Stilted Rainbow", which is now in the process of being published. Here is a summary of my life.

I was born in Toronto in July 1956. After 11 long years and nearly giving up hope of ever having a child, my mother finally had the baby she was wishing for, and my father had the son he could be proud of.

Son? Did I say son? Yes, you heard correctly! I was born a boy (or so they thought). My parents had no idea of the troubles to come!

Life has always been a challenge for me. As a young child, I had very poor motor co-ordination. I had no hand preference, and I could not dress or feed myself until I was 4 years old. In school, I was particularly challenged in writing skills, (I used my left hand to guide the pencil in my right hand, and would press so hard that I was forever breaking off the points).

Physical activities such as ball games, skipping, or requiring balance were almost impossible for me. I was always dropping or spilling things and would bump into walls or people or stumble a lot. A physical examination by our family doctor revealed that I had an unusual co-ordination pattern known as "Cross Lateral". This meant that my left eye, right hand, and left leg were the dominant ones. Because of my poor co-ordination, my muscles were weak, and needed to be strengthened. I had difficulty with perception, which explained my difficulty seeing and bumping into things.

Other observations included; walking on a slant, nervousness, difficulty paying attention, looking at people with blank unseeing eyes or not looking directly at people at all, a tendency to shut people out or withdraw inward, and rhythmically banging my head or repeatedly rocking back and forth when frustrated.

Communicating with me as a child was also difficult. I did not learn how to speak until I was 3 years old, and I never used any baby talk prior to that. I cannot remember just how I communicated with my parents before I spoke, but even at 6 years of age, I still did not speak clearly.

I began to learn how to read around age 4. At first, I would read from the bottom of the page to the top, and from the right to the left. Sometimes I would read things upside down. Gradually over time, I slowly learned how to properly read a book. Other problems in reading which affected my writing as well were; reversing letters, mirror imaging, and misreading or misprinting words by leaving out letters. These reading and writing difficulties, which I've largely overcome, are known as Dyslexia.

Before I began school, I was socially withdrawn, but for a short time I did have a couple of playmates, Sharon and Christine. I naturally related to girls more than boys, and did not understand the aspects of the boys' rough style of playing. Mind you, there were some aspects of playing that girls that did I just couldn't understand either, such as "tea sets" and "plastic dolls". How can one be so involved in serving tea that isn't real, and talking to someone that isn't there, or playing with a plastic doll, pretending it is real when it clearly isn't? Christine's mom had a real baby, who fascinated me far more, and I went over many times to see and help with the baby.

When I did play with girls, we would skip or play hopscotch (I was forever stepping on the lines or tripping on the rope). Sometimes we would play house, I, being a "boy" would be selected as the father, but I always rejected the father role, as somehow it did not seem right for me. (This was one of the earliest indicators that my gender identity was in conflict, long before I understood or identified people by gender. I was 5 years old at the time). Most of the time, I played on my own. I preferred being on my own much of the time as I had difficulties understanding how to see things from other people's viewpoints, and this led to many conflicts with my peers.

Up until I was 4, I was not allowed outside of the house alone. My mother had a great fear of what I just might do, and rightfully so. Rules and limits were difficult for me to understand. I could not comprehend the rules unless I knew exactly why I should be following them in the first place. This caused a great deal of conflict between my parents and I, and learning the rules was not easy. My mother had her hands full with things like chasing me off the street, which I would run onto without knowing I was supposed to look first (slap), doing or taking things when I didn't know I was supposed to ask permission first (slap), drawing all over the walls in our hallway (slap). How was I to know this was wrong when Sharon's mom had drawn a beautiful mural on hers?

The fact that I didn't know the same type of rules applied to different situations equally, made things very confusing for me. I always seemed to be getting punished for something or other, and most of the time, I felt that it wasn't justified. I now know that my parents were trying their best to try and protect me in a situation that must have been very frustrating for them.

Back in the early 1960's people believed that a "bad child" was a sign of "bad parents", so my parents must have carried much guilt over me. My parents did not have the literature and resources we have today, and the medical profession wasn't of much help either. I loved my parents very much even though as a child I was frustrated and hated them at the time, because I felt they couldn't understand and were rejecting me. I just wish they were alive today so they could realize it wasn't their fault.

I was always getting into things or into trouble. One example was when I was four years old; I attempted to ride my tricycle down the basement stairs. Well I made it to the first landing, but as I tried to go down to the basement, the tricycle flipped over and I landed head first on the cement floor. My parents rushed me to the hospital, where I had sutures put in my forehead and a nice big painful lump to remind me never to try that again!

What I learned in one situation didn't necessarily connect with another. When I was five, my father was fixing something on the garage roof. I was curious as to what he was doing and what it was like on the roof. He would not let me go up; anyway as fate would have it, my father went in the house for something, leaving a rather tempting ladder. It was too tempting, so I climbed up to the garage roof. I liked being on the roof. You could see things far away, and I felt on top of the world, even though it was only 16 feet high. Just then my father returned, saw me on the roof and yelled "get off the roof immediately!" Big mistake! Being a literal thinker and not knowing a sense of heights, I jumped off! My father turned as white as a sheet, and I landed on the grass. I was not hurt, but my father was not impressed either. I was sent inside for the rest of the day (slap).

Closets and cupboards had a special meaning for me. As a child, this was my special hiding place where I could sit and be free from the world. I loved sitting in the dark closet behind the hanging clothes, alone to think about the world or just to be. Sometimes I would get in trouble when my parents came to retrieve an article of clothing and got the scare of their lives upon finding me in there. I knew they were in the room, and might possibly find me, but I didn't care as this was my hiding place and I wasn't about to move. When I was a little older and we had moved to a new house, I had my own spot in a crawl space under the basement stairs. I had a carpet, a lamp, games, toys and other things to keep me entertained for hours, and also to keep the rest of the world out.

Closets were more than a place to hide in. There were always interesting things to explore. Mysterious boxes of unknown stuff, old papers and letters, funny hats, and lots of clothing. My world was full of things to explore, and sometimes at other people's houses too! Closets were full of different clothes. I loved trying on my father's police shirts and hats, but I really enjoyed my mother's dresses and clothing. I could not

understand why boys and girls had to dress differently. I did not have a sense of a gender. I was just me. It was not until puberty at age twelve that I would be forced into one.

When I was old enough to play by myself outside, I liked to explore our backyard and look for things to do. One was to taste and eat different things such as flowers, grass, and dirt. I soon found these delicacies inedible, but the grass wasn't too bad though. At the cottage, my father taught me how to find wild raspberries, strawberries, and mint leaves. These were a treat that I could really eat.

While at the cottage, I liked to play in the sand on our beach. I could spend hours on end making elaborate road systems going all over the place, complete with villages, small mountains, detours, and twig bridges. I did not need anything else to occupy me or play with. I did not need cars. I enjoyed making the roads. This led to my fascination of "where do roads end?" When I was older I liked to explore them and trails as well.

Seeing the "spots", many autistic people see these spots. Air molecules I called them. Billions of tiny round dots, like we are swimming in a sea of them. White circles with a black dot in the center, and at night I would see them too, as tiny stars. I would think of far away places and galaxies, until I finally fell asleep. I can still see them today.

Patterns and colors have a way of drawing me into them, just as looking at the spots, I could easily get lost in the pattern of wallpaper and drapes, and sometimes clothing too. Some shades of colors I was deeply drawn into, especially metallic ones like candy apple red on bicycles. Shiny things like chrome I could stare at and get lost in, sometimes my parents had to yell or even physically move me to get my attention when I was lost in these things.

I used to drive my parents crazy with repetitive sounds. One of the earliest things I remember was having a small metal clicker that I would continuously "click" around the house. Finally in exasperation, my parents took it away from me. Not to be outdone, I learned how to flick my tongue inside my mouth and could imitate the clicker. My parents were at their wits end. My parents had an old floor model radio that I called the "squealer". It had a short wave band on it, and when I was old enough to figure out how to work it, I liked to tune it in between the short wave stations to hear the squeals and squelches coming out of the radio. I also liked to move the dial or volume up and down to make funny repetitive sounds. By this time my parents would be screaming at me to get away from the radio, but I liked what I was getting lost in. Usually they ended up having to chase me away from it, but I always sneaked back to it later, and eventually I learned to keep the volume lower so I wouldn't get caught as quickly.

If I thought my early childhood and difficulties with my parents were bad enough, my nightmare was just about to begin. I was five years old and was starting school. Nothing had prepared me to be thrust into a small room with twenty or so other children. I was frightened. I had never been around so many other kids in my life. I was used to being on my own. This caused a great deal of stress on me, and I had difficulties in the classroom.

One of the first things I noticed (remember this was the early 1960's) was that boys and girls played in segregated groups. I was used to playing with girls, so I approached their group, but to my surprise they promptly rejected me because I was a "boy". I felt very hurt by this and I couldn't understand why. The teacher tried to get me to play with the boys, but they did not want me and rejected me as well. (The boys knew there was something different with my gender and my expression of it, long before I even knew or understood what differences in gender were all about). I was left to play on my own. I felt vulnerable alone and scared. I wanted out of school, I did not belong with these people who took pleasure in picking on or bulling me when they saw an opportunity.

It was about this time my behavioural problems began. I had quickly learned to retaliate to bullying, sometimes in a violent way such as hitting, kicking, or even throwing something at the offending person. I was not very good at being discreet, so the teacher would often isolate me from the rest of the class. The teacher would not listen to my explanations, and neither would my parents. I began to develop a great fear and mistrust of authority, which still haunts me today.

In grades one and two, we were confined to small desks placed in neat rows and I felt confined and trapped. Being nervous and hyperactive, I could not sit still in a desk for long periods of time. I would have to get up and move around and the teacher would yell at me to get back in my desk. The sounds of the classroom echoed all over the place, distorting what the teacher was saying. If anyone else would talk or whisper, I had great difficulty trying to decipher just what the teacher had said. Often I was accused of not paying attention, even though I was trying my hardest.

My oversensitive hearing interfered with my ability to process information correctly. Loud noises would startle me. Certain frequencies that didn't seem to bother other people actually hurt my ears, and still do to this day. My eyes were always darting around the room and it was difficult to pay attention to one thing. I was always taking in information whether consciously or not, from all sources. This would delay my ability to process information quickly, as I was bombarded by both good and useless information that I could not filter out from the important stuff. At times, this made me look like an idiot in class, when the teacher would finish discussing a subject and ask questions in the classroom. Eventually I would be asked, and I would be sitting there with a blank look on

my face because I couldn't immediately recall what was said or sometimes even the subject. If I was asked the same question at a later time, after I had time to process it, I could go off like the Encyclopedia Britannica on the subject.

Sometimes I knew things that I didn't even know I had learned and had stored away. Later on something would trigger it and I could go on and on about a subject that I didn't even know I knew anything about. This is what I call "Unknown Knowing".

In the classroom, I would talk to myself. This was a way to try and keep myself focused or to understand what the teacher was saying. The other kids would tease and make fun of it, and the teacher would yell at me to stop mumbling in class. By this time, the whole classroom was in laughter.

My peers probably thought I was crazy. My frustration was so great that I began to act out. I was fed up with being made to feel stupid in front of my classmates just because I did things differently than them. I began to hit and poke at the kids who said bad things about me and I started to shut out the teacher and all authority. I was beginning to retreat into my inner world to escape the classroom that was overwhelming me.

Repetitive behaviours helped me to escape. I repeatedly banged my feet against my desk, sometimes for periods of twenty minutes or more, or covered my ears for up to fifteen minutes at a time while the teacher was trying to talk to me. I also had a tendency to stare at the woodgrain of my desk for prolonged periods of time and I had to be threatened or physically manoeuvred by my teacher to get my attention. When angered, I would kick or punch walls, tear my books, throw things, or crayon all over my desk.

Recess time was difficult for me. I mostly stayed by myself. I did not know how to make friends and many times I was pushed around and bullied. One time on my way home from school, a kid threatened to stab me with a knife. It got to the point that I did not feel safe in the schoolyard. I began staying inside at recesses, reading books in the library.

Because of my outbursts in class, many times I was placed behind an isolation screen or sent down to the principal's office. I enjoyed the isolation as I could concentrate on my schoolwork more easily, and soon found grade one work to be boring. My teacher began giving me grade two work to do. I enjoyed the challenge. If I could be away from a classroom setting, or isolated, I could learn better in my own way.

Eventually being in the classroom was too much for me, I had become too out of control, and retaliating against my peers had escalated. I would now lash out by hitting them with

yardsticks, throwing books, pencils, erasers, shouting, and knocking desks over. Finally I had to be removed from school, especially after destroying the principal's office.

The school board sent a teacher to our home, to try and educate me. Her name was Mrs. G. She was able to understand me and help me relate to people better. I also was able to overcome a lot of problems I had with dyslexia. Learning on a one-to-one basis, I was able to excel at my own pace as long as I could be motivated.

At the insistence of the school board, I was sent for psychological testing and sessions at a Psychiatric Hospital, Children's Unit. (Doesn't this sound like a nice place to visit?). With the help of our family doctor, the testing was arranged. The original tests showed that I had a severe brain pathology, mental retardation of an unknown etiology, brain damage, and childhood schizophrenia. My I.Q. showed an average intelligence of 99. I was seen periodically between February 1963 to May 1966.

In the fall of 1965, it was recommended by the hospital that I should be placed in an institution for children with behavioral problems. My parents fought this decision, and instead were able to get the hospital to try me out at a new school. My parents were told, if for any reason the trial sessions did not work out, and if I had to be removed from the school, the hospital was prepared to take legal action, to have me placed into the institution.

Despite the insurmountable odds, I managed to be accepted into their program. I was now back in a classroom, but it was sad having to say good-bye to Mrs. G. I now had a new teacher who was a great mentor to me. He did not see me or my other classmates as problems. He saw and encouraged the good things in us, and strived to bring out the talents in each of us. He sensed my search for acceptance, and at first I hesitated in approaching him. After a while I was able to learn that I could trust him, and his caring attitude motivated me to learn how to change some of the behaviours troubling me. Through the help of the teachers and staff, I was slowly beginning to learn how to relate to my peers.

One of the problems I had in relating to people or my peers was my intense focus on special interests and hobbies. Unless we had a mutual interest in something, it was very difficult for me to communicate. This has been a problem all of my life, the fact that I tend to go on and on about a topic, without knowing when to stop. Today I'm a lot better at catching this habit. For most of my life, my hobby of collecting licence plates is where I was intensely focused. People didn't matter to me during that time; I was more orientated to objects. It was safer but lonely.

After three years and passing grades five and six, it was felt that I could finally return to a regular school. It was no easy task for me leaving the protected setting I had been in. Junior high and high school were not good times for me, especially with the upheavals to come.

The first challenge I had to overcome was getting used to changing from one classroom to another. I was forever getting lost, mixing up my days and schedules, and ending up in the wrong class. Hallways were a nightmare, with the students all changing classes at once. It seemed like a stampede of cattle coming at me, which would overwhelm my visual sense, and cause a partial shutdown. This greatly shortened my visual range, and I would see only distorted parts of people going by me. (This still affects me today in crowded situations). Many times I would be late for my next class because I would wait in a classroom or washroom until it was safe enough in the hallway.

Another interesting thing I've found is when my sensory systems get too overloaded, I can feel a disconnection from my body. Even if the overload has happened earlier, I can suddenly seem to lose my place in time and space. At these times it's as if I have to feel my way while walking.

Auditory overload has always been a big problem for me. The school auditorium and cafeteria were overwhelming to my oversensitive hearing. The constant jumble of words over top of one another, the clatter of dishes and trays would scramble my ability to think. Even today malls, bars, and other noisy places will very quickly overwhelm me.

High school was supposed to be a social place to connect with others and make friends. I had a social blindness in which I could not read messages in facial expressions or body language. Because of this, many students would try to take advantage of my naiveness. There may have been some students who genuinely wanted to get through to me, but there were many more with hidden agendas that were waiting for an opportunity to embarrass or humiliate me. Since I could not read their intentions, it was safer not to get close to anyone.

Another thing happened to come along and caused a great upheaval in my life. It was called puberty. I could sense that something was very wrong and I wasn't developing as I thought I should. Up until this point I didn't relate myself to a gender; I was just myself. If anything, I related and felt more towards girls and women, but I didn't actively pursue it. Now my body was being forced into a gender, and not what I thought it would be.

Like most changes, I did not take well to it. Girl's bodies were developing differently than mine, and I didn't know why. I began to feel alienated and confused with myself. I

had many questions but no one to turn to for help. As I began to develop, I began to grow hair on my face and all over my body. This made me feel like a gorilla or the wolfman. My voice remained high, and I did develop small breasts, but I wasn't like the other girls, and I felt betrayed as I began to turn into a man. It was like turning into the monster in the horror movies.

Back at school, some of the girls in class would tease me in suggestive ways, which I felt uncomfortable about. I was attracted to some of them, but I also envied them and felt shut out from their world, even though I felt the same as them. I never dated during my high school years and basically I have not had any intimate relationships in my life.

As time went on, I became very cold and uncaring with my classmates. In the past I would clobber anyone who picked on me, but now I did not know how to defend myself from their teasing and harassment. My classmates never knew of my gender conflict, but I still felt like the nerdy leper of the whole school. Finally it was too much. Between the raging male hormones making me violent and aggressive and the situation I found myself in on a daily basis at school, I was beginning to revert back into what I had worked so hard to grow out of. I wasn't able to learn anything in school anymore, so I ended up dropping out of school at the end of grade 11.

Now there was one person just before I left school who would stand up and defend me from the onslaught I faced. Her name is Lotte and we have been friends now for the past 30 years. Through knowing her and helping raise her three children when her marriage broke up, I learned how to love and care for another person. After I left school, I felt very cold and uncaring towards other people. Only those I knew were the exceptions. I was confused with my gender. I tried valiantly to live up to society's viewpoint that I was supposed to be a man, but I was clearly a square peg trying to fit into a round hole.

I managed to cope through all of this by becoming extremely focused in my hobby of collecting licence plates. People were not important to me at this point in my life. Focusing on my hobbies was safer than dealing with the world.

With a fellow collector, I travelled all over North America to antique shops, car flea markets, and licence plate conventions over a period of 20 years. My last two major trips were to the Northwest Territories in 1989 and Labrador in 1991. Through these trips, talking and meeting people with similar interests, I slowly began to come back into a world of people.

With the great help from Lotte, and her kids, I experienced having a family life that helped me become the caring and open person I am today. Lotte's children now think of me as one of their parents and I consider their children as my grandchildren.

Over the last 20 years I have worked for the Toronto District School Board as a caretaker, and I must thank my union (Canadian Union of Public Employees), local 4400 and previously #1265 who were there every time I stuck my foot in my mouth with the management.

In June 1994, I transitioned from my "male" self to my new identity as a woman. I now feel much more comfortable with myself, and have never looked back. There was still one thing that remained unresolved, but I didn't know what it was at that point in my life.

In March 2000, a chance comment by my works supervisor, " I can't teach you common sense. You either have it or you don't", sent me on a quest to unlock the mysteries of my childhood. At first I thought I might have Attention Deficit Hyperactivity Disorder, but in seeing a specialist, we soon found there was more. It seemed that I had an Autistic Spectrum Disorder known as Asperger's Syndrome.

At the Geneva Centre's conference on Autism in 2000, I met Dr. B., who was able to help me understand my condition and was able to give me a diagnosis of Asperger's Syndrome in 2001. Since then I now have a better understanding of myself, and I now want to help others like myself.

Some of the things I'm doing or involved in include: The Trans-autism Research Project which is affiliated with the Canadian-American Research Consortium on Autistic Spectrum Disorders, being involved with the Geneva Centre for Autism and the adult support group, writing my autobiography "Stilted Rainbow" (I hope it gets published soon). I have written 30 poems. I'm studying neurology and genetics with an interest in developmental disorders. I've also written seven medical papers relating to autism and gender identity disorders and I'm an activist in and out of my union, C.U.P.E., for people with hidden disabilities, and fighting for human rights and dignity for transsexual people.

It has been a struggle for me throughout my life, and Dr. B. calls me a survivor.

Sometimes miracles can happen. Since writing this summary, I now find myself in a relationship with a wonderful man and writer. His name is John. At age 47, I never thought I would ever have a relationship but since we both have Asperger's Syndrome, we understand each other. I never thought it was possible. My story has a happy ending, and a new beginning.

GREEN GRASS

A fictional account by Beth Vosskuhler

Daniel Gray sat in the observation room playing with blocks. He wasn't building anything, at least not what other children might build with blocks. He made rows of neat piles. Piles so neat they looked like a six-year-old couldn't have made them. But he'd been on that project for more than an hour, totally oblivious to anything else. He had the concentration of a scholar, but the things that he chose to use that concentration on were a bit odd. He had his blocks, puzzles, and toys like other children, but he didn't really play with them. He simply placed and kept them in extremely fastidious order. That was only one of the things that kept his parents and psychologists scratching their heads.

And that's why he and his parents were at this place, an institute for the study of child psychology, on opposite sides of a one-way mirror, his parents with a guru by the name of Dr. Fitzgerald. "Let me see some more of Daniel, Mr. and Mrs. Gray. Why don't the two of you head to the waiting room? I want to ask Daniel some questions." Mr. and Mrs. Gray went where they were told. In recent years they had grown accustomed to listening to psychologists and blindly accepting anything they said.

Dr. Fitzgerald then went into the observation room. "Daniel?" she called out. He didn't turn his head. She went over to him, pulled up a chair, and sat down. She moved all of the blocks away and picked up Daniel's chin so that he was facing her. His eyes were bright, limpid pools of blue, but they looked right past hers. He saw her nametag and immediately started to finger it in a way that would have gotten a normal child slapped. "Stop that, Daniel."

At this point Daniel's mind was going on as usual. He was thinking "The limb on the tree..." Dr Fitzgerald wondered what he was thinking and asked "How are you, Daniel?"
"The tree in the hole..."
"It's a nice day, isn't it?"
"The hole in the ground..."
"Would you like to play a game?"
"And the green grass grows all around all around and the green grass grows all around."
"OK Daniel, that's enough for today."
"That's enough," Daniel parroted back.

Dr. Fitzgerald then gave Daniel back his blocks and left him at his task of piling them neatly. She then went out to the waiting room and motioned for Mr. and Mrs. Gray to come and sit with her. "I'm sure now. Daniel is autistic."

"What does that mean?" they both asked.
"Well, he will never lead a normal life, but since he does speak the prognosis will at least be better than what is average in these cases. Does he speak much?"
"Yes. He loves nursery songs. He's always singing 'Bah bah black sheep' or something," Mr. Gray answered.
"Then you should be thankful for that."
"THANKFUL?! What do you mean 'thankful'? So what if he can sing the Fisher Price top 40?" shouted Mrs. Gray as she burst into tears. "I don't even know if he knows who we are, let alone loves us like we love him."
"This is never easy for parents to hear, and it's not easy for me to say. I'm sorry. Here, I've got some numbers of support groups..."
"That's enough. Could we just get Daniel and go?" asked Mr. Gray. He was always a to-the-point kind of guy.
"Suit yourself, but if you change your mind, call." Dr. Fitzgerald answered calmly. She had too much experience with this sort of thing.

In the car on the way home, Mr. and Mrs. Gray heard a small, alien voice in the back seat sing the words, "...and the green grass grows all around all around and the green grass grows all around."

It wouldn't be the last time.

LIVING WITH ASPERGER SYNDROME

by Gary Waleski

I live in Oakville, and am presently employed at Sheridan College, working on the telephone switchboard. I have lived a challenging life, dealing with many hardships with many different situations, being different for unknown reasons and unable to mesh smoothly into society. Ultimately, they were all learning experiences.

Through conversing with people, I am surprised to learn that nobody seems to remember being a baby. I, however, remember my days as a baby very well. I remember sleeping in a crib, sitting in a highchair, eating from a Gerber jar, drinking from a baby bottle, and many other things that go along with being a baby. I was born in the late sixties, and I remember clearly what was "in" at that time. I remember seeing cars that are now known as classics and the clothes that people wore in that time. Mostly, I remember constantly hearing the music of those days. The first song that I ever recognized was "Hey Jude" by The Beatles, being only a year old when that song was on the charts.

As a child, I carried on with many repetitive actions. One thing I used to do was move a toy car back and forth on the table for a long period of time, and I vaguely remember watching the spinning motion of its wheels. My repetitions became rituals and they always had to be followed through; otherwise, I became very upset.

A major problem with me as a child was my temper tantrums. I easily became upset when things did not work out the way I anticipated. I was irritated by situations that included my rituals being broken, transitions, being disciplined, being ridiculed and disapproved of, being left out, and a time or activity of pleasure being ended. Such situations caused me to resort to screaming, crying, swearing, and stomping. Sometimes I experienced undesirable consequences. Teachers sometimes reprimanded me for being noisy, and neighbours sometimes complained to my parents about my screaming out profanities. I threw those fits simply to express my feelings and displeasure, hoping that people would co-operate with me, but it never worked.

Hypersensitivity created unusual fears for me. I was often traumatized by unexpected or excessive noise. I was often afraid of audio equipment, even though I always loved music! I was frightened by static, or the noise resulting from the needle not landing properly on a record. Power tools and equipment in use often terrified me. The sound of an air-raid siren, or even a train whistle, spooked me. I was even frightened of toilets! I made a point of staying away from washrooms as long as I had no need for them. In fact, I found many objects looked frightening to me, in one way or another - for practically

unknown reasons! Sleeping was a problem for me throughout my childhood, since I had nightmares very often. Being spooked was one of my major stresses.

I was extremely hypersensitive to taste, and extremely picky with food. There were only a few certain foods that I loved as a child. My taste buds were so sensitive that many foods tasted bad to me. If it didn't taste right, I was totally unable to ingest it. My parents were very strict about making certain that all our dinner was finished, so suppertime was often a bad time for me.

I was also hypersensitive to touch, and therefore, very sensitive to pain. When I was really little, I used to get so uncomfortable and resist whenever my mother washed my face. Going to see my family doctor was a major ordeal to my parents and I. Some of my doctor's methods of checking me were very uncomfortable. Whenever we went to see him, as soon as we got to the parking lot, I recognized the building, and that was it. My parents had a tough time getting me out of the car, into the building, to the waiting room, and worst of all, into the examining room. I was violently kicking and screaming all the way! It must have been an entertaining show for all the other patients to watch! In my early years, visiting the doctor was the worst times in my life.

I made some accomplishments and displayed talent. In Grade 3, at the age of eight, I created a pastel mural of "The Cat in the Hat," which impressed the teacher and all of my classmates. This art piece was taped on the window of our classroom door for the entire school to see. My drawing skills became the one thing that my peers complimented me about. In Grade 8, our class was in detention, and in order to be excused, one student had to memorize an entire poem. After many students failed, I made an attempt and got it correct, dismissing the class from detention. There were numerous other achievements, such as perfect test scores and high efforts in games that were impressive to others.

Things that were superficial to other people, especially as a child, fascinated me. I used to be mesmerized by windshield wipers in motion and I used to always stare at running fans. The basement of our home was my entertainment centre as a child. I would watch our sump pump whenever it was running and I would inspect our furnace whenever it was active. I would observe and memorize the actions of our washer and dryer as they went through their cycles.

A major hobby of mine as a child was making inspections to fulfil my interests. Whenever we visited friends, I would go through their basement looking for such items of interest. I used to go around the neighbourhood inspecting chimneys, clothes dryer exhaust vents, and sewers. I used to go through all of the ditches, watching water pour out of sump pump drainpipes and flow through culverts. I often called on neighbours,

asking to see their basement utilities and laundry appliances. Some people knew me well and gladly complied, while some were unpleasant, telling me to get lost and slamming their doors in my face. I must have been quite the pest.

I drove many people crazy, talking only about my interests. I often socialized with my neighbours, mostly talking and questioning about items that included appliances and basement utilities. Other children did not want to socialize with me, since they were unimpressed about how I was turned on by these interests.

I was an extreme introvert throughout my life. As a toddler, I objected to excessive interaction from people outside of my family. I was extremely shy, and became uncomfortable whenever people acknowledged me. Most adults have the tendency of mimicking babbles of young children. However, I hated it when people mimicked me. I found it annoying, and if only I knew how, I would have said, "I don't need a parrot!"

Throughout elementary school, I had no desire to socialize with other children, and I spent recess time occupying myself in solitude. I had childhood friends in my neighbourhood, but I never wanted to socialize with them. Whenever people called on me, I would either turn them down or hide someplace. I was intimidated by the responsibility of entertaining other people and I needed time and space to myself. Whenever other children became persistent on spending much time with me, I became repelled by them. In lieu of playing with other children, I preferred to watch TV or live in a make-believe world at home.

I was an avid daydreamer ever since I was a child. I used to design for myself, a highly complex fantasy world. I pretended that my house was an individual town and I populated this town with make-believe people and characters from TV sitcoms and cartoons. These people were my real friends, as opposed to the people from the real world. I liked them because they were exactly what I wanted them to be. I pretended that I was an adult, married with children, and that my actual bedroom was my own house. My fantasy world was a perfect world; everything being the way I wanted it to be, providing me an escape from the hardships of reality.

My fantasies continued and evolved as I became a teenager, but the purpose remained the same. I lived the customized life that I wanted to live, escaping from the real world. I fantasized about the things that I always wanted, which included being popular, owning a car, and having a girlfriend. I always fantasized about the future, thinking about the optimistic hope of my life changing for the better. I fantasized about moving to a new town and starting a new life. I fantasized about being highly successful and making an immense amount of money. I dreamed of owning a beautiful home and raising a perfect

family. Fantasizing was like an addictive drug; it was a wonderful high and allowed me to forget about the stressful times.

Since I entered adulthood I outgrew my fantasy world, and with my increasingly busy and active lifestyle, I don't have much time to fantasize. However, during idle times I tend to drift off into thought, which is what happens with everybody. I sometimes enjoy reminiscing about the good times in my past. I often think about the things that I hope to acquire in the near and distant future. I think about landing a successful career that I would enjoy. I think about where I would like to live, and how my life would evolve. It's the optimistic thoughts that keep me going.

I was misunderstood to be a lazy child, since I was unable to understand and exercise motivation and sense of responsibility. Nearly all of my time was spent fantasizing and watching TV, and everything else was of little priority to me. I failed to keep in mind about hygiene, and my parents often had to get after me to keep myself groomed. My parents also had a rough time getting me to co-operate with domestic chores. Whenever they asked me to do anything, I would complain and argue, often causing a confrontation. That's an example of unwanted transitions; I had a hard time accepting being interrupted in order to participate in a task. I could not handle studying for school, due to confusion and intermittent attention span, and that created a negative impact on my grades.

School was a major problem for me during my growing years. I faced severe difficulties with my studies, and ultimately had an extreme dislike towards school. I was intimidated by the workloads, peer pressure, and the treatment from the teachers. I felt that I was imprisoned, and preferred to be at home fantasizing and watching TV. I was unable to pay attention in class, and often couldn't bring myself up to doing homework. The teachers added to the problem, chasing me on a regular basis. They would yell at me, strike me, and deliberately humiliate me before my peers. (I certainly hope that our school system has evolved since those medieval times.) As a result of my challenges, my grades suffered. I failed Grade 4 and several high school courses, and usually averaged slightly above passing. Report card day was seldom a good one for me.

One of my biggest problems in school was peer pressure. Children can be the cruellest people in the world, being able to find everything different about someone and capitalizing on it. I was a prime target because of the many situations about myself. Since I was unable to gain social skills, my peers noticed that I was behind. Since my mannerisms were quirky, my peers always mimicked me.

Since I struggled in school, my peers considered me to be stupid. Since I had eccentric interests, my peers considered me to be weird. And since my sense of personal hygiene was inconsistent, my peers considered me to be a slob.

My reputation in school made me totally unattractive to girls. No girl would ever consider dating me; and in addition, many girls ridiculed me. I have been attracted to many different girls, but I only ended up heartbroken. In my early adult years, I developed the courage to ask out girls, but I was always unsuccessful in landing a date. I tried joining extracurricular activities in hope to meet girls, but there were never any in my age group. It took me until mid-adulthood to finally find a significant other.

I have received counselling many different times throughout my life. When I was six, my parents sent me to see a child psychiatrist. The autism spectrum was not well known in the seventies, and this doctor came to the conclusion that I was highly intelligent, but lacking in motivation. I was diagnosed as sanguine. He recommended introduction to responsibilities (e.g. tidying my bedroom, setting/clearing the dinner table, etc.) and strict discipline. He designed a demerit-oriented system to motivate me to keep on top of my responsibilities and maintain good behaviour. I would acquire demerit points for misbehaving and neglecting responsibilities. If I exceeded a couple demerits in a week, I would be penalized by forfeiting certain privileges. However, there was a reward for good consistency -- I would not be punished. I was seeing this doctor for many years, and as time went on, he became impatient with me. I was not progressing in maturity, still living in a fantasy world, and struggling in my studies. If things were not to improve immediately, he advised my parents to send me to military school. As a result, I was living my childhood in fear and intimidation.

When I was a teenager, I was severely stressed over my problems at home and in school. My family doctor sent me to see a guidance counsellor. It was not a major affect on my life, but he was a person for me to talk to. He tried to boost my self-esteem, and gave me advice on social skills and directions to minimize stress.

Occasionally, I entered times of severe depression for no apparent reason. In the early nineties, I began experiencing extreme cases of depression, and was unable to pinpoint the source. This continued to occur regularly for over two years. The worst thing that I found about depression was the mystery of it - not being able to understand why it was happening. Over that period of time, I was regularly seeing a psychiatrist, who prescribed me anti-depressants. Once I was diagnosed with AS, it was agreed that my depression may possibly be related to it. The mystery was now gone and I began to see things in better perspective, and after a few years, I no longer had a need for psychiatric care.

Employment was a complicated issue for me as a teenager. I landed my first job one summer when I was 17, in a distribution warehouse. It was a difficult situation for me to adjust to, since I never worked before. I was used to having my summer holidays throughout my life, and was looking forward to the freedom again this year. Suddenly, I had to wake up early and report to this place everyday through the whole summer, and this was something that I did not like. It was like going to school through the summer, only worse! In addition, I was having a lot of difficulties with this job. I first thought it was like high school, but then I quickly realized it was much tougher. I often came in late, like I did in school, but got severely reprimanded for it. I also was unable to comprehend instructions, and they often became very impatient with me. I was constantly pressured to keep up the pace, which often fluctuated. It was a very rough way for me to be introduced to the work force.

After I graduated from high school, my parents had a difficult time getting and keeping me employed. I was extremely reluctant to have a job, since it was far beyond my state of comfort. I did not want to go to a strange place everyday to take on undesired tasks. As well, being a sensitive person, I was always terrified of supervisors. I preferred to be at home, where I was comfortable. I never understood the importance of money until I began supporting myself. Since my parents were supporting me, I did not care whether or not I had any money at all. It was always so hard for me to make the transition from a free lifestyle to a regimented schedule. The only job I really wanted, and could handle at that time, was one that wasn't too demanding. When my parents made me go out to look for work, I would bike around town stopping at very few places and partially filling out applications. They also looked through the papers finding employers for me to contact, which I did against my own will. All that I wanted throughout my growing years was total freedom and minimal stress. During that time, I have been through temporary successes and failures in employment.

I maintained a casual winter job at the CN Rail for three years. My duties entailed removing snow and de-icing chains on the flat cars that the Ford Plant used for shipping their newly-made vehicles. I did not mind that job, since the workload was not too demanding and the pay was high.

I began my employment at Sheridan College when I was 19. I was a casual summer employee, setting up offices and repairing furniture over the summer break. I worked at that job for two summers, and I quickly became accustomed to it and began to enjoy working there. Nobody was overly demanding with me, and the duties were all straightforward. This became a very familiar place for me, and I got to know and like many of the people there.

After I worked there for two summers, an opening for a permanent position in the Shipping & Receiving Department was posted, and I immediately bid on it and was hired. I was extremely happy since I was now permanently employed in familiar surroundings and there was no longer an uncertain future for me. I worked there for six years and it became a routine lifestyle for me.

I attended Sheridan College for the first time in the late eighties, studying in Major Appliance Servicing. I chose that program because of my interest in laundry appliances. The curriculum was not too complex and I did not experience many difficulties in the program. I successfully completed the program; however, I did not embark on any career relating to my studies. I decided that it was not my preference.

I bought my first car when I was 20. It was a 1978 Plymouth Volare 2-door with a "Slant 6" engine. I found it to be an amazing experience for me to finally own my own set of wheels. For the first while I became "car happy," driving this car all of the time - even when I had no place to go! I was so proud of my car. Sadly, it lost its life in an accident two years later.

In the early nineties, my parents retired and moved to Dunnville, a small town in the Niagara area. They made home in an upstairs apartment of a building that they owned in town. As opposed to selling the house in Oakville, they allowed my brothers and I to rent it. Even though I was living in the house that was owned by my parents, and one that I was raised in, I was officially living on my own. I had no problem adjusting to it, and I handled all of the responsibilities with minimal difficulties. This became proof that I could look after myself with no special guidance or supervision. This was the time that I became an adult.

I continued to experience some difficulties through my adulthood. One lifelong problem of mine that persisted was my inability to deal with people assertively. I had often accepted wrongful treatment from other people, as opposed to standing up for myself. Being a sensitive person, I always wanted to avoid a confrontation and remain on good terms with everybody. Unfortunately, many people noticed that in me and took advantage of it, pushing as far as they could get away with. It is sad how some people in this world operate, and personally, it angers me.

A major problem that I had to deal with as I was maturing was my lack of self-esteem. In dealing with most young adults my age at the time, it appeared to me that I was far behind in knowledge and life experience. In the years before my diagnosis, I could not figure out what was wrong with me and I was blaming myself. I struggled to catch up, but I did not know how. It was that, along with the negativity that I have received

throughout my life that has left me down on myself. There were times when I have felt so low that I have become physically sick.

My temper continued to be a problem for me, often going off over trivial issues. Whenever I was inconvenienced in any way, I would either yell out profanities, or hit something, or both. I also had a tenancy to go on a vicious tirade whenever a family member approached me in a manner that I did not like. I often ended up feeling embarrassed over my fits.

My condition was finally discovered when I was in my twenties. One day, my brother was watching Shirley, a TV talk show, and the subject was on autism. He noticed that many of the characteristics matched my own, so he sent for a transcript and obtained a phone number to one of the doctors on the show. My mother contacted the doctor, who referred me to a psychiatrist in Hamilton. When I met with this doctor, he confirmed that my characteristics matched those of Asperger's Syndrome. Upon knowing this, a heavy weight was lifted from my shoulders. It was great to actually know and understand what has been going on with me and I was no longer blaming myself for my challenges. This became the turning point in my life.

In the mid-nineties, I once again attended Sheridan College, studying in Executive Office Administration. This course had created a major positive impact on my life. It was in that program that I acquired my knowledge in computers and software, and that's when I bought my first computer. This program has also taught me skills in business communications, letter formatting, and public speaking, all of which come in handy for my current projects.

My motivation and confidence greatly increased through this program, and I was constantly studying whenever I was home. My interest in these studies was so high that I actually enjoyed putting all of this time into it. It is ironic that after years of my family chasing me to study, they were now trying to make me slow down!

The course has also improved my social experience, and I was very popular with all of my classmates. None of them seemed to notice anything odd about me whatsoever. Most of my classmates were girls, so I have learned a lot about interacting with people of the opposite gender, which became helpful for me in dating. It was a major boost on my self-esteem to be liked by many girls, and also to be able to handle a university-level program. I look at those days, as my second chance to enjoy the "happy school days" that I never had the first time around. I graduated from this program with good standing.

After school, I resumed employment at the college, working part time in Distribution Services. I worked in that department until the spring, when I accepted my present job at the switchboard. The work is straightforward, and it took me almost no time to get it down pat. In the beginning, I found it to be an intimidating experience in dealing with irate callers. And as well, for the first while, my intermittent attention span complicated things a bit. I was often missing important information, and therefore, frequently making mistakes. As a result, others have become impatient with me at times. Over the years, I feel I have improved in those areas, and have developed the confidence to be tactful and make demanding callers realize that I am the one in control. I've now been at this job for several years. Today, I feel that, in many respects, I have come a long way. I am living independently and working at a full-time job. I can handle all of my responsibilities, including shopping, projects, and financial issues, with minimal help. I can do anything that any neurotypical adult can do, such as support myself, maintain a job, and drive a car. I am well educated, with two college diplomas. In many ways I am just like anybody else, and my challenges have little effect on that.

I lead an active social life, having a large circle of friends. Some of my oldest friends are people that I have known from high school. Many of my friends are long-time friends of my brothers - and my brothers have many friends. When I was a child, there was a large age gap between them and I, but since I have grown up, the gap has closed and I am now in the circle. Recently, as I have mentioned, I have met many friends from college. I also have some friends who are deaf, and I am presently practising sign language. My signing skills are somewhat slow, but I can basically communicate. Through recent involvements, I met a number of friends who are also on the autism spectrum. And, I can happily say that I now have a girlfriend.

I still presently experience some difficulties due to my challenges. I am an exceptionally sensitive person. I become easily hurt when involved in a personal confrontation. I also tend to become paranoid and think the worst if times seem a bit challenging. My temper is a major problem for me. I still easily lose it whenever I am inconvenienced in any way. My self-esteem also hits its lows at times.

I am very hypersensitive to sound, often becoming startled and annoyed by sudden or loud noise. Unfortunately, I cannot escape it, but I do take certain steps to lessen certain noisy situations for me. For example, whenever I shut my car off, I always make a point of turning off the radio so that it does not blast me whenever I start my car again. We have a chiming clock, which at countless times, I have thrown corks at. I can turn the chimes off; but then, I may as well turn off the fridge, the furnace, the dishwasher, my family members' voices, and everything else in the house that makes any noise. It would be an awkward path to take, but at least, the place would be nice and quiet.

I have difficulty accepting transitions. When my mind is set on something, I prefer if things turn out exactly as I anticipate. I have an electronic planner that I live off, and I schedule my life around it. I plan my days far in advance, so if anybody needs me, they have to make an appointment. It becomes very difficult for me whenever something suddenly comes up, and I find it hard for me to readjust. I prefer to be notified in advance about any change of plans whenever possible.

I still prefer my solitude much of the time. I am sometimes very territorial about my space, and tend to become annoyed whenever it is invaded. When I first get up in the mornings, it takes me a little time before I am comfortable interacting with anybody. I also have my own little TV room, where I can spend my time alone. I spend most of my evenings there, as well as other times when I need my space, which is often. That little room is my sanctuary, which is a necessary part of my life.

My mannerisms can use some fine-tuning. When speaking, I tend to use over-exaggerated gestures to accompany my speech. I also have a tenancy to drift off, especially in a large crowd in public. People sometimes have to wave a hand in front of my face to call my attention. I have even been cut off from being served alcohol because I was mistaken for being intoxicated. However, I have no problem when conversing one on one with an individual. Perhaps it is the obligation to respond that motivates me to stay in tune.

My attention span is inconsistent. Sometimes I can only focus on something for a limited time, and then my mind wanders. At other times, I tend to be mesmerized by something simple, and not fascinated with others. I can only focus on one single thing at a time, and have difficulties paying attention to or performing multiple things. This causes difficulties for me when keeping track of important things, such as my finances. If my finances were the only things I had to keep track of, then I would have no troubles with it. Unfortunately life doesn't work that way; I have many things to have to keep track of. After being caught up with my finances, I'll forget all about it and lose track once again. One of my big weaknesses is keeping track of my money, which is scary. I just need to find a way to balance my attention equally.

I do not mean to instil any pessimism in anyone; I am simply sharing all of my experiences with you - negative and positive.

Over the recent years, I have developed a major interest for a career in helping people on the autism spectrum. I feel that being on the spectrum myself, and having progressed as much as I have, I would be a great asset in guiding people on the spectrum in a promising

direction. I would like to assist in giving children on the spectrum the opportunity to proper help at a younger age.

Being on the spectrum myself, I have the advantage in being able to understand and relate to them. As well, I see myself as living proof that if I can be successful, there is a positive future for anybody on the spectrum. I am a member of Autism Society Ontario (ASO), taking on the role as Chair of the Newsletter Committee. I also participate in various other functions of ASO. To name a few; I participate in such functions as garage sales and bike-a-thons, and volunteer as one of the coaches in baseball for autistic children. In addition, I have given many presentations for different organizations, including the Geneva Centre. My involvements have given me much experience and a very rewarding feeling. Fortunately, the autism spectrum is becoming recognized and understood, so today's children on the spectrum have the major advantage in being properly treated and guided. My dream is to assist in giving these children the happy and fulfilling maturing years that I never had. I did not let my challenge defeat me, and I am determined not to let it defeat the others!

In my opinion, autism does not seem to be a complex situation. I believe that it is not much more than just a maze that must be simplified, and I believe that it can be done through skilful counselling. In all neurotypical people, the human brain has an amazingly high capacity for intelligence, and it is extremely thirsty for knowledge. It rapidly absorbs and processes any information fed into it. A neurotypical child grows up constantly absorbing all of the information that he or she is exposed to, steadily gaining experience and wisdom. In people who are developmentally challenged (e.g. Downs Syndrome), the brain has a limited capacity for intelligence, and processes information at a slower rate. People on the autism spectrum, however, have the same brain as in neurotypical people. However, this condition forms a maze-like pattern of communication between the brain and the senses, causing the brain to absorb only selected pieces of information. With the limited information that it does gather, this powerful brain will process it and clarify it to amazingly precise detail. This may explain why autistic people have incredible memory in certain subjects.

The emotions of a person on the spectrum seem to be magnified, compared to a neuro-typical person. Strong emotions, such as anger and fear, may be rather traumatic for the individual. As well, the individual tends become mentally withdrawn in order to escape reality. This usually starts at a young age, and the emotional hardships of life bring this on. I believe, however, that this situation can be reduced with treatment, especially at a young age.

I honestly do not know what it is like to be like the majority of the human population who are neurotypical. In turn, all of the neurotypical people truthfully do not know what it is like to be on the spectrum. The feeling may be quite similar, and yet, it may be altogether different. However, I do not look at autism as a disability, but simply a way of being. I also believe that people on the spectrum can be assisted to function more easily in this "norm-oriented" society. They may have to think and practice differently, but I do not think it is impossible to bridge the gap. The techniques may not be totally figured out as yet, but if we have come this far, imagine what we will be able to achieve down the road! The future looks hopeful, and I honestly believe that there is a light at the end of the tunnel.

FINDING A PLACE TO BE

by Martine Stonehouse

Finding my place to be,
was always a struggle for me.

Wanting to fit in,
But not knowing how,
People would confuse me,
I didn't know why.

I wanted to speak,
The words would not come.

I wanted to heat,
I could not understand.

I wanted to touch,
But I could not feel.

I wished for a way to connect with your world,
But it was safer in mine.

A world of special interests, objects, and possessions,
People were far from my mind.

In my prison of life,
I thought I was free,
The world had lost its meaning for me.

But being alone and afraid,
I began to plan my escape.

I tore down my walls,
And through out the bars,
Then I looked to the world from afar.

In the distance, I could see someone familiar to me,
Could it be?
Someone like me?

Yes, there are people like me,
We're autistic you see.

I'm so happy,
Now I've found my place to be.